Doctorate in Clinical Psychology

Understanding Post-Traumatic Growth in Neurodegenerative Conditions and Dementia

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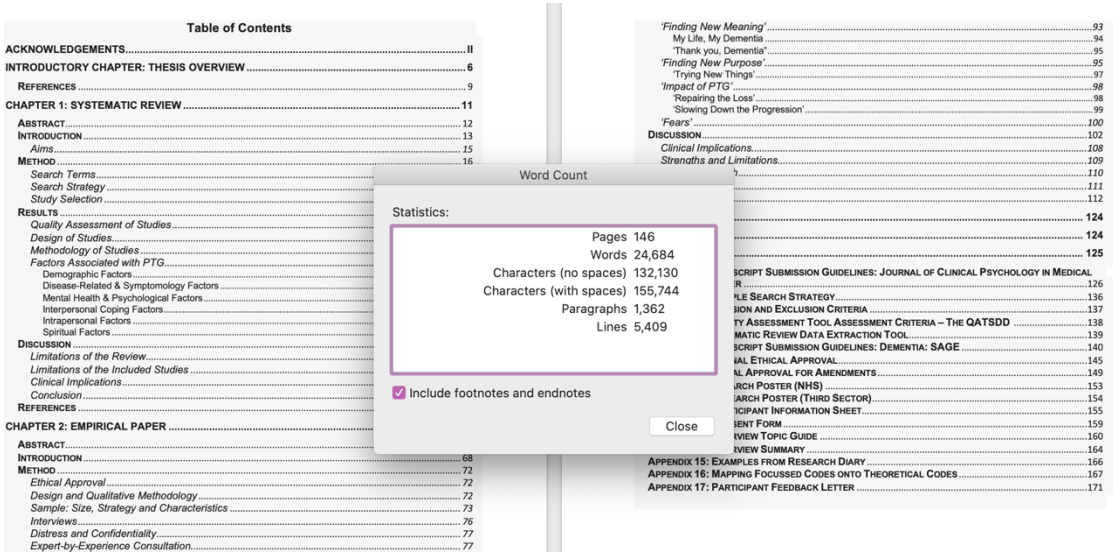

INTRODUCTORY CHAPTER: THESIS OVERVIEW

Post-traumatic growth (PTG) is a relatively new construct which has been receiving increased attention in both research and clinical circles (Tedeschi et al., 2018). Tedeschi and Calhoun (1996) defined PTG as the benefits that can occur from the struggle that is experienced when an individual attempts to adjust following a traumatic or highly challenging life event. PTG theory is influenced by personal construct theory, schema theory, assumptive world models, and existential philosophy (Tedeschi et al., 2018).

Previous research has explored PTG in a variety of contexts, including in relation to combat veterans (Tedeschi, 2011; Tsai et al., 2015), sexual assault (Ullman, 2014; Ulloa et al., 2016), road traffic accidents (Salter & Stallard, 2004; Wang et al., 2012) and natural disasters (Dursun et al., 2016; Schneider et al., 2019). More recently, it has begun to be explored in a variety of health-related contexts, such as cancer (Stanton et al., 2014; Thornton & Perez, 2006), HIV/AIDS (Milam, 2004; Murphy & Hevey, 2013), brain injury (Kinsella et al., 2015; Powell et al., 2007), and stroke (Gangstad et al., 2009; Kelly et al., 2018).

This thesis consists of a systematic review and an empirical research paper. The systematic review was prepared for submission to the Journal of Clinical Psychology in Medical Settings (Appendix 1). Systematic searches were completed, and a narrative synthesis was conducted to integrate the existing quantitative, qualitative, and mixed methodology literature on the experiences of PTG in people living with a neurodegenerative condition (NDC), namely Parkinson's disease, multiple sclerosis, and motor neurone disease/amyotrophic lateral sclerosis. Thirteen papers met the identified inclusion criteria and were quality assessed using the Quality Assessment Tool for Studies with Diverse Designs (QATSDD) (Sirriyeh et al., 2012) (see Appendix 4). Identified factors included: demographic factors; disease-related

and symptom factors; mental health and psychological factors; inter- and intra-personal factors; and spiritual factors.

The empirical paper was prepared for submission to Dementia (Appendix 6). This paper utilised grounded theory to explore PTG in people living with dementia. A theoretical model of the findings was created, which diagrammatically represents the process of PTG and the factors influencing this experience. Factors included peer support, involvement in meaningful activity, and being able to construct a new narrative for themselves, their lives, and their dementia. Participants felt that these factors had helped to slow down the progression of their dementia, whilst also repairing many of the losses they experienced when initially diagnosed.

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CHAPTER 1: SYSTEMATIC REVIEW

The Experience of Post-Traumatic Growth in Degenerative Neurological Conditions

Charlotte Cooper

Prepared in accordance with guidelines for submission to Journal of Clinical Psychology in Medical Settings

Abstract

Neurodegenerative conditions (NDCs) are complex and progressive in nature and have a wide symptom profile impacting physical, cognitive, emotional, and behavioural functioning. The narrative surrounding living with these conditions is largely negative, with research having previously documented the impact on psychological wellbeing and the significant loss accompanied with a diagnosis of a NDC. Post-traumatic growth (PTG) is a term used to describe the positive transformation which can occur following a traumatic event. It has been applied to several different health related contexts. The aim of the current review is to systematically review the current literature relating to PTG in NDCs. Five electronic databases were systematically searched for relevant studies. A total of thirteen studies were deemed to meet the inclusion criteria and were subject to narrative synthesis. The factors associated with PTG were categorised and included: demographic factors; disease-related and symptom factors; mental health and psychological factors; interpersonal factors; intrapersonal factors; and spirituality factors. The included studies evidenced PTG in NDCs is possible, however there appeared to be inconsistencies with regards to the exact factors which may influence a person's experience of growth. Interpersonal factors such as social support and family support were consistently found to be a positive factor in the experience of PTG. Further longitudinal research, with consistently defined and measured variables, is required to investigate the phenomenon further.

Introduction

Neurodegenerative conditions (NDCs) involve progressive degeneration of nerve cells within the central and peripheral nervous systems, including the brain (Goldstein & McNeil, 2013). These diseases can impact an individual's movement, language, and cognitive abilities such as memory and attention (Ovaska-Stafford et al., 2021); the dementias, Parkinson's disease, and multiple sclerosis are examples of NDCs. These diseases are complex, with their aetiologies remaining largely misunderstood, and although symptoms may be able to be controlled, the diseases themselves are incurable (Cummings & Pillai, 2016). NDCs largely have an individualistic impact on those diagnosed with them, however they are all progressive in nature, meaning they cause a gradual decline in cognitive, psychological, and physical functioning, and can result in early death (Ovaska-Stafford et al., 2021).

Much of the literature describes the negative impact of NDCs on those diagnosed. For example, depression and other forms of psychological distress are reported to be common in multiple sclerosis (Hart et al., 2008; Patten et al., 2003), Huntington's disease (Craufurd et al., 2001; Paulsen et al., 2005), Parkinson's disease (Reijnders et al., 2008), Amyotrophic Lateral Sclerosis (Rabkin et al., 2005), and Alzheimer's disease (Zhao et al., 2016). The progressive and changeable nature of NDCs can cause uncertainty and fear about the future, which can further impact an individual's level of psychological distress (Garroway, 2015; O'Rourke, 2012). Furthermore, it is largely accepted that a diagnosis of a NDC comes with a significant level of loss, including both tangible (i.e., jobs, friends) and existential (i.e., independence, identity) losses (Bjornestad et al., 2016; Harris & Keady, 2009; Macleod et al., 2016; Roach & Drummond, 2014).

Post-traumatic growth (PTG) is a term originally coined by Tedeschi and Calhoun (1996), describing the process by which people who have experienced trauma can be positively transformed and 'grow' as a result of their experiences. Tedeschi et al. (2018) acknowledged that PTG broadly occurs within five key areas: relating to others; new possibilities; personal strength; spiritual change; and appreciation of life.

PTG has been examined in several neurological (Gangstad et al., 2009; Grace et al., 2015; Powell et al., 2012) and non-neurological health conditions (Stanton et al., 2006; Sawyer et al., 2010; Wang et al., 2021). Grace et al. (2015) conducted a systematic review and meta-analysis aiming to examine the extent to which demographic variables, injury factors, cognitive processes and psychological health were associated with PTG in individuals who had experienced ABI. They examined eight studies and found that older age, employment status, education level, relationship status, increased time since injury, higher levels of life satisfaction and psychological wellbeing, lower levels of depression and subjective beliefs about change post-injury were all significantly associated with PTG following ABI. Females and those with lower levels of anxiety were also found to experience higher levels of PTG, however the effect sizes here were very small and not significant.

Research around PTG has grown substantially over the last decade; and while research exploring the concept within NDCs is increasing, it is still in its early stages and is heterogeneous. Therefore, a systematic review of the current literature is needed to synthesise what is currently known about growth and how PTG may differ in NDCs. Previous research exploring 'growth' within NDCs has tended to use PTG-related terms, such as 'meaning making', 'sense making', and 'personal growth', all of which may neglect to acknowledge the 'traumatic nature' of NDCs.

PTG has been well-studied in several clinical health populations and in neurological conditions which have resulted from an external trauma (e.g., traumatic brain injury). It has been suggested that the experience of PTG may vary greatly depending on the health condition and therefore a greater understanding of health-related trauma is needed (Barskova & Oesterreich, 2009). Due to the organic cause and progressive nature of NDCs, it is possible that the experience of PTG may differ to other health-related traumas.

Aims

The aims of this paper are to systematically review the quantitative and qualitative literature exploring PTG in NDCs, in order to answer the following questions: 1) how is PTG experienced by individuals living with an NDC?; 2) what factors are associated with PTG following a diagnosis of an NDC?

Method

Search Terms

Initial scoping searches identified appropriate search terms (see Table 1 below). Broad search terms were used to capture the range of labels used to describe PTG and to ensure a wide variety of NDCs were captured. Wildcards were used to ensure all permutations were captured, and Medical Subject Headings (MeSH) were used when required (see Appendix 2 for example search strategy). Search terms related to PTG were identified from scoping searches. Previous systematic reviews conducted on PTG with other clinical populations were also examined to identify those terms closely aligned with PTG, which may not have been found during scoping searches.

Table 1: *Search Terms used in Systematic Searches*

Post-traumatic growth	"post traumatic growth"; "personal growth" "positive growth"; "psychological growth"; "perceiv* growth"; "perceiv* benefits"; "benefit finding"; "stress related growth"; "adversarial growth"; "sense making"; "meaning making"; "flourishing"
Neurodegenerative conditions	"neurodegenerative diseas*"; "neurodegeneration"; "dementia"; "Parkinson's disease"; "Alzheimer's disease"; "Huntington's disease"; "Multiple Sclerosis"; "Motor Neuron* Disease"; "Amyotrophic Lateral Sclerosis"; "Lewy Body Disease"; "Creutzfeldt-Jakob Disease"

Search Strategy

This review was undertaken and reported in line with the Preferred Reported Items and Meta-Analyses (PRISMA) (Moher et al., 2009) guidelines. Once scoping searches were complete, the following electronic databases were systematically searched: PsycINFO; Medline; CINAHL; Web of Science; and SCOPUS. Initial searches were conducted in March 2020 and were re-run in April 2021. The reference

lists of identified papers were also examined. Following discussions with the research team, it was decided that unpublished (i.e., grey) literature would not be examined as part of this review due to time constraints and difficulties in adequately assessing quality. Once the aims of the review had been decided and the search strategy was clarified, the review was registered on PROSPERO (date of registration: 6 July 2020).

Study Selection

All studies (*n* = 1391) identified from initial database searches were transferred into EndNote referencing software. Once duplicates were removed, the titles and abstracts of 609 articles were screened. A second reviewer [SB] independently replicated the screening of titles and abstracts. Full-text articles were requested for 61 papers which were found to be relevant following the title and abstract screening. Full-text articles were then reviewed by the first author [CC] to identify whether they met the inclusion and exclusion criteria (see Appendix 3). The second reviewer [SB] reviewed half of the included articles against the inclusion and exclusion criteria to ensure the reliability of the eligibility assessment. There were two discrepancies between the first author and second reviewer, which were resolved through discussion. Following this, 13 articles were deemed to meet the objectives of this review. This process can be seen clearly in the PRISMA flowchart below (see figure 1).

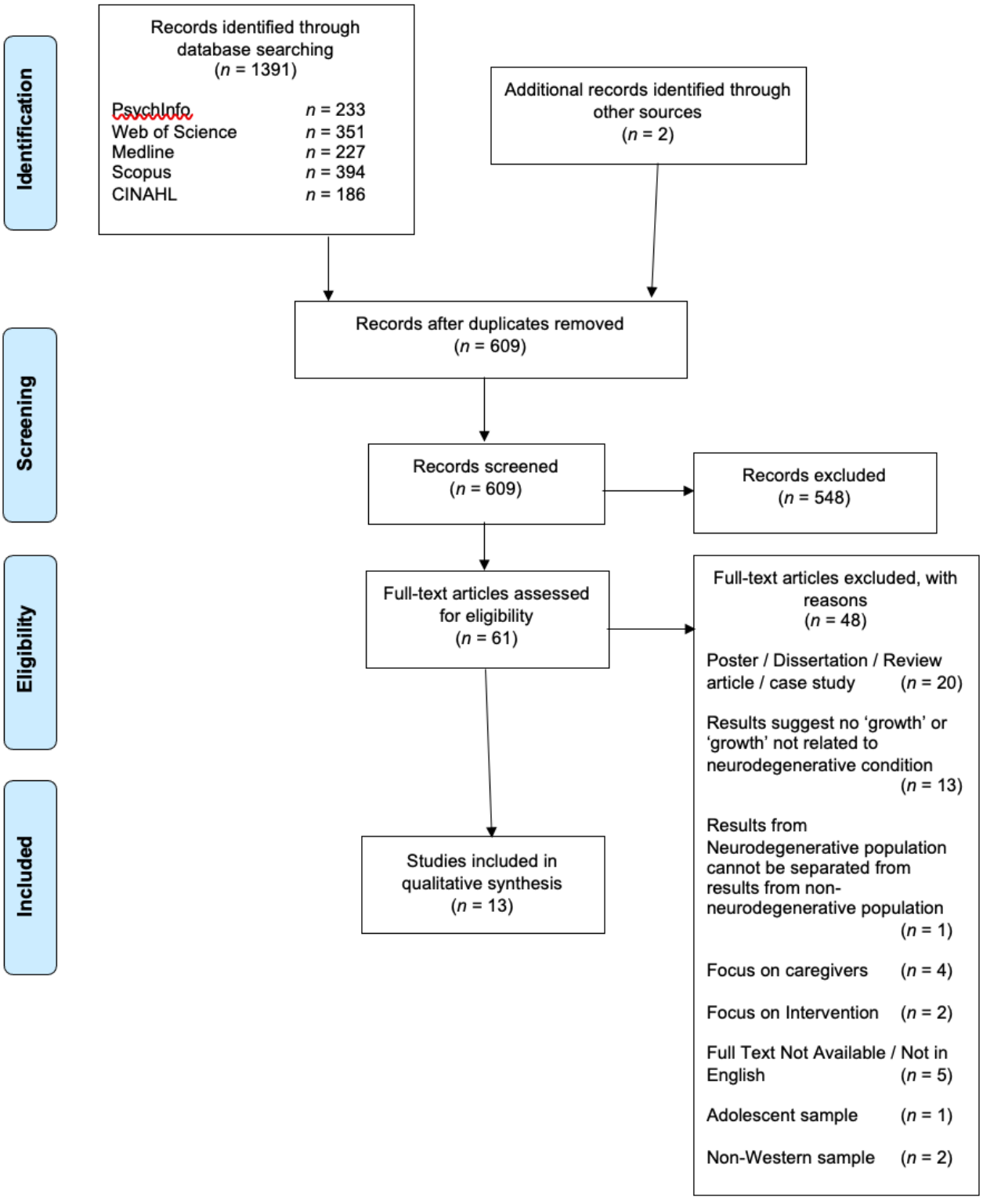
Inclusion and Exclusion Criteria

Articles were included if they discussed factors associated with PTG, or a related term, and if at least part of the sample had a NDC and were analysed as a separate group. Each study's definition of PTG or the related term was assessed to

see if it captured the participants' growth from before to after their diagnosis. Studies which used the included search terms (see Table 1) but did not operationalise them in a way which examined the psychological development or growth of participants were excluded; as a result, articles which exclusively examined concepts such as 'resilience' or 'quality of life' were excluded as these constructs are regarded as being qualitatively different to the phenomenon under exploration (Tedeschi et al., 2018). Review articles, dissertations, posters, case studies, and articles not published in English were also excluded, as were studies where participants were aged under 18. Research published before 1995 was also excluded as this is the year when research into PTG first began; and studies which focussed solely on carers or specific interventions were also not included (see Appendix 3 for full inclusion and exclusion criteria).

Method of Synthesis

A narrative synthesis of the data was undertaken as it allowed for information from a variety of methodologies and approaches to be synthesised together (Popay et al., 2006; Ryan, 2013). The narrative synthesis was completed with the aid of a data extraction tool (see Appendix 5), which allowed for key details from each study to be extracted. Information relating to study aims, participant characteristics (including key demographic data), study location, design and analysis were tabulated and can be seen in Table 3 below. Once completed, the data extraction tool findings for each study were analysed in detail to explore relationships both within and between the different studies using mind maps.


Identification
Screening
Eligibility
Included
Records identified through database searching (n = 1391)
PsychInfo n = 233
Web of Science n = 351
Medline n = 227
Scopus n = 394
CINAHL n = 186
Additional records identified through other sources (n = 2)
Records after duplicates removed (n = 609)
Records screened (n = 609)
Records excluded (n = 548)
Full-text articles assessed for eligibility (n = 61)
Full-text articles excluded, with reasons (n = 48)
Poster / Dissertation / Review article / case study (n = 20)
Results suggest no 'growth' or 'growth' not related to neurodegenerative condition (n = 13)
Results from Neurodegenerative population cannot be separated from results from non-neurodegenerative population (n = 1)
Focus on caregivers (n = 4)
Focus on Intervention (n = 2)
Full Text Not Available / Not in English (n = 5)
Adolescent sample (n = 1)
Non-Western sample (n = 2)
Studies included in qualitative synthesis (n = 13)

Results

A narrative synthesis was conducted on the included studies and six relevant factors were identified (demographic factors, disease-related and symptom factors, mental health and psychological factors, interpersonal factors, intrapersonal factors, and spirituality factors) which will be discussed in detail below.

Quality Assessment of Studies

Articles were quality assessed using the Quality Assessment Tool for Studies with Diverse Designs (QATSDD) (Sirriyeh et al., 2012). The QATSDD is a critical appraisal tool frequently used to quality assess studies of mixed methodologies. The tool consists of 16 criteria; 14 of which apply to quantitative studies, 14 to qualitative studies, and all 16 apply to mixed methodology studies. The reviewer is required to rate each research paper on a scale of 0-3 for each of the criteria. Each paper is then given a total quality score, which is out of 42 for quantitative and qualitative papers and 44 for mixed method papers. This total score is converted into a percentage to allow quality to be compared across all included papers, regardless of methodological design. The findings of this quality assessment can be seen in Table 2. A third reviewer [EB] was employed to independently assess 7 of the included articles chosen at random. The agreement rate between the two reviewers for overall quality was 84%. The quality assessments from both the author and the third reviewer were reviewed and discussed to determine the exact areas of discrepancy. Upon discussion, it was found that there were only small qualitative differences between the quality assessments of the two reviewers which seemed to reflect the subjective nature of the assessment tool. Therefore, an 84% agreement rate was deemed to be acceptable.

The quality assessment revealed most of the included studies received a quality percentage within the range of between 74 and 77%. The study perceived to

be of the lowest quality was completed by Mohr et al., (1999). This was the oldest paper included, having been conducted over 22 years ago, and it is possible that the way research is evaluated and presented has changed over time, which may have impacted on the quality score. All the included papers failed to acknowledge the role of service involvement in their designs and did not evidence how they considered sample size in their analysis; failure to acknowledge these points significantly impacted quality scores.

It is important to highlight that Pakenham (2005) and Pakenham (2007b) used the same sample, as did Pakenham (2008), Pakenham and Cox (2009) and potentially Pakenham (2007a) in terms of the Time 1 data. Therefore, many of the results contained within these studies are repeated and this has not always been made clear. Where possible, the author has attempted to highlight this below.

Additionally, one study recruited a sample which consisted of two clinical populations: people living with MS; and people living with Rheumatoid Arthritis (RA) (Evers et al., 2001). Within the published paper, the results did not always differentiate between those findings related to the MS sample, and those from the RA sample. Therefore, there are several results reported below where the findings from people living with MS could not be separated from people living with RA; where this is the case, the author has stated this, but these results must be interpreted with caution as the inclusion of another clinical sample may have skewed the results from the MS sample.

Table 2: *Findings from Quality Assessment**

QATSDD Tool Factor	Mohr et al., (1999)	Evers et al., (2001)	Pakenham (2007b)	Ackroyd et al. (2011)	Pakenham (2005)	Pakenham (2007a)	McBride et al. (2008)	Pakenham & Cox (2009)	Mock & Boerner (2010)	Mavandadi et al. (2014)	Pakenham (2008)	Vescovelli et al. (2020)	Stutts et al. (2020)
Explicit theoretical framework	2	3	3	3	3	3	3	3	3	3	3	3	3
Statement of aims/objectives in main body of report	2	3	3	3	3	3	3	3	3	3	3	3	3
Clear description of research setting	3	3	3	3	3	3	3	3	3	3	3	3	3
Evidence of sample size considered in terms of analysis	0	0	0	0	0	0	0	0	0	0	0	0	0
Representative sample of target group of a reasonable size	2	1	2	2	2	2	3	2	2	1	2	2	3
Description of procedure for data collection	2	2	2	2	2	2	3	2	3	2	2	2	2
Rationale for choice of data collection tool(s)	2	3	2	3	2	2	2	2	2	3	2	3	2
Detailed recruitment data	2	2	3	2	3	3	3	3	3	2	3	2	3
Statistical assessment of reliability and validity of measurement tool(s)	0	3	0	3	2	N/A	0	2	3	2	2	2	2
Fit between stated research question and method of data collection	2	2	3	3	3	N/A	3	3	3	3	3	3	3
Fit between stated research question and format and content of data collection tool	N/A	N/A	N/A	N/A	N/A	2	N/A	N/A	N/A	N/A	3	3	N/A
Fit between research question and method of analysis	2	3	3	3	3	3	3	3	2	3	3	3	3
Good justification for analytic method selected	0	2	3	2	3	3	3	3	3	3	3	3	3
Assessment of reliability of analytic process	N/A	N/A	N/A	N/A	N/A	2	N/A	N/A	N/A	N/A	2	3	N/A
Evidence of user involvement in design	0	0	0	0	0	0	0	0	0	0	0	0	0
Strengths and limitations critically discussed	2	2	2	2	2	3	3	2	1	3	3	2	3
Quality Score	21	29	29	30	31	31	31	31	31	31	37	37	33
Quality %	**50%**	**69%**	**69%**	**71%**	**74%**	**74%**	**74%**	**74%**	**74%**	**74%**	**77%**	**77%**	**79%**

* Studies reported in order of quality (high-low)

Design of Studies

Thirteen articles met the inclusion criteria and reported results on PTG in NDCs (Ackroyd et al., 2011; Evers et al., 2001; Mavandadi et al., 2014; McBride et al., 2008; Mock & Boerner, 2010; Mohr et al., 1999; Pakenham, 2005, 2007a, 2007b, 2008; Pakenham & Cox, 2009; Stutts et al., 2020; Vescovelli et al., 2020).

Sample sizes ranged from 25 (Mavandadi et al., 2014) to 477 (Pakenham, 2005); the total sample size across all studies, including those with duplicate samples, was 3,080, with a mean sample size of 236.9. The mean disease duration or time since diagnosis ranged from 3.6 years (Mock & Boerner, 2010) to 10.25 years (Ackroyd et al., 2011). Nine of the included studies examined multiple sclerosis (Ackroyd et al., 2011; Evers et al., 2001; McBride et al., 2008; Mohr et al., 1999; Pakenham, 2005, 2007a, 2007b, 2008; Pakenham & Cox, 2009), three Parkinson's disease (Mavandadi et al., 2014; Stutts et al., 2020; Vescovelli et al., 2020), and one Amyotrophic Lateral Sclerosis (Mock & Boerner, 2010). Table 3 shows the design characteristics of each study.

Table 3: *Design Characteristics of Included Studies*

Author, *year* (Location)	Main aim of study	Design and Analysis	Sample (*n*) and Characteristics	Neurodegenerative condition	PTG or related term	Time since diagnosis	Measure of PTG
Mohr et al., *1999* (USA)	To better understand how patients with MS view the effects of the disease on their psychosocial functioning	Mixed	***n* =** 50 *(part A)*; 94 *(part B)* **Age:** *Part A: Mean* = 40 years (SD = 8.44); *Range* = 25-67; *Part B: Mean* = 42.6 years (SD = 9.18); *Range* = 18-66 **Gender:** *Part A:* Female *n* = 33 (66%); Male *n* = 17 (34%); *Part B:* Female *n* = 70 (74.5%); Male *n* = 24 (25.5%)	Multiple Sclerosis	Benefit-Finding	Part A: Mean = 9.1 years (SD = 6.80); Range = 1.7 - 28.7 years Part B: Mean = 8.1 years (SD = 6.4); Range = 6 months – 30 years	Part A: Two-open ended questions Part B: The statements from above to rate on a Likert scale
Evers et al., *2001* (Netherlands)	To develop a short, reliable, valid questionnaire for assessing the a priori constructs of helplessness, acceptance, and perceived benefits in patients with chronic diseases	Quantitative; Questionnaire design	***n* =** 167 **Age:** *Mean* = 40.6 (SD = 8.8); *Range* = 21-67) **Gender:** Male = 33%; Female = 67%	Multiple Sclerosis	Perceived Benefits	Mean = 9.4 years (SD = 5.9); Range = 0-29	Impact of Rheumatic Diseases on General Health and Lifestyle (IRGL) Impact Scale
Pakenham, *2005* (Australia)	To examine the direct and buffering effects of benefit finding on both positive and negative outcomes after controlling for the effects of relevant demographics and the stress and coping predictors: illness parameters, problem context, and stress appraisal	Quantitative; postal questionnaires	***n* =** 477 *(Time 1)*; 404 *(Time 2)* **Age:** *Mean* = 47.77 years (SD=11.48); *Range* = 18-78 **Gender:** Female *n* = 365 (77%); Male *n* = 109 (23%)	Multiple Sclerosis	Benefit Finding	Mean = 117.24 months (SD = 98.94); Range = 3 - 624	Benefit Finding Scale

Pakenham, *2007a* (Australia)	To examine the dimensional structure of a multi-item measure of sense making in people with MS	Quantitative	***n* =** 388 *(Time 1)*; 296 *(Time 2)* **Age:** *Mean* = 49.33 years (SD=11.31); *Range* = 21-80 **Gender:** Female 81%; Male 19%	Multiple Sclerosis	Sense Making	Not reported	One closed question
Pakenham, *2007b* (Australia)	To examine the adequacy of the Benefit Finding Scale as a comprehensive measure of benefit finding in MS and to further explore the nature of benefit finding in MS	Qualitative; postal survey	***n* =** 477 *(Time 1)*; 404 *(Time 2)* **Age:** *Mean* = 47.77years (SD = 11.48); *Range* = 18-78 years **Gender:** Female *n* = 365 (77%); Male *n* = 109 (23%)	Multiple Sclerosis	Benefit Finding	Mean = 117.24 months (SD = 98.94)	Benefit Finding Scale
McBride et al., *2008* (Northern Ireland)	To assess the factor structure of the SLQ-38	Quantitative; postal questionnaires	***n* =** 260 **Age:** Not reported **Gender:** Male *n* = 72; Female *n* = 188	Multiple Sclerosis	Adversarial Growth	Not reported	Silver Lining Questionnaire
Pakenham, *2008* (Australia)	To explore the nature of sense making in MS using qualitative data	Mixed	***n* =** 388 **Age:** *Mean* = 49.33 (SD = 11.31); *Range* = 21-80 **Gender:** Female (*n* = 313) 82%; Male (*n* = 68) 18%	Multiple Sclerosis	Sense Making	Not reported	A series of closed- & open-ended questions
Pakenham & Cox, *2009* (Australia)	To examine the dimensional structure of the Benefit Finding in Multiple Sclerosis Scale	Quantitative; post questionnaire	***n* =** 388 **Age:** *Mean* = 49.33 (SD = 11.31); *Range* = 21-80	Multiple Sclerosis	Benefit Finding	Not reported	Benefit Finding in Multiple Sclerosis Scale

			Gender: Female (*n* = 313) 82%; Male (*n* = 68) 18%				
Mock & Boerner, *2010* (Canada)	To examine patient-caregiver pairs in the context of ALS, and the association of sense making and benefit finding with number of depressive symptoms	Quantitative; surveys	***n* =** 52 patient-caregiver pairs **Age:** *Mean* = 58.28 (SD = 12.56)* **Gender:** Male = 63%* Female = 37%*	Amyotrophic Lateral Sclerosis	Sense Making & Benefit Finding	Mean = 44 months (SD = 26)	Open-ended questions
Ackroyd et al., *2011* (UK)	To investigate whether patients with MS and their partner showed adversarial growth	Quantitative cross-sectional design; questionnaires	***n* =** 72 pairs of patient and partners **Age:** *Mean* = 47.5 **Gender:** Male *n* = 30 Female *n* = 42	Multiple Sclerosis	Adversarial Growth	Mean = 10 years 3 months (SD = 9.3)	PTGI
Mavandadi et al., *2014* (USA)	To examine the association between perceived benefit finding and marital quality among dyads of individuals with PD and their spouses	Quantitative; questionnaire	***n* =** 25 patient/spouse dyads **Age:** *Mean* = 72.3 (SD=10.0)* **Gender:** Not reported	Parkinson's Disease	Benefit Finding	Mean = 11.8 years (SD = 7.0)	Benefit Finding Scale
Stutts et al., *2020* (USA)	To describe levels of self-compassion, optimism, and post-traumatic growth in individuals with Parkinson's Disease	Quantitative; online survey	***n* =** 140 **Age:** *Mean* = 68.72 (SD = 7.62); *Range* = 47-86 **Gender:** Male *n* = 79 (56.4%) Female *n* = 59 (42.1%)	Parkinson's Disease	PTG	Mean = 7.15 years (SD = 5.34); Range = 4 months to 23 years	PTGI
Vescovelli et al., *2020* (Italy)	To investigate PTG in PD patients using both quantitative and qualitative methods	Mixed	***n* =** 54 *(quant)*; 49 *(qual)*	Parkinson's Disease	PTG	Low PTG (*n* = 12) Mean = 5.3 (SD =4.6);	PTGI

			Age: *Range*: 52-84 years **Gender:** *Quant:* male = 38 (70.4%); female = 16 (29.6%) *Qual:* male = 33 (67.3%); female = 16 (32.7%)			Medium PTG (*n* = 30) Mean = 6.4 (SD = 4.5)' High PTG (*n* = 12) Mean = 7.8 (SD = 7.0)	

Methodology of Studies

Ten of the thirteen studies included were of quantitative methodology, one used a qualitative approach and two were mixed methodology. The included studies used a range of measures to evaluate PTG and related concepts, with the Post-Traumatic Growth Inventory (PTGI) (Tedeschi & Calhoun, 1996) and Benefit Finding Scale (BFS) (Antoni et al., 2001; Mohr et al., 1999; Pakenham & Cox, 2009) being the two most common tools utilised.

The PTGI is a 21-item questionnaire comprising of five subscales related to the five domains of PTG: 'Relating to Others' (e.g. *"I have more compassion for others"*); 'New Possibilities' (e.g. *"I developed new interests"*); 'Spiritual Change' (e.g. *"I have a better understanding of spiritual matters"*); 'Appreciation of Life' (e.g. *"I have a greater appreciation for the value of my own life"*); and 'Personal Strength' (e.g. *"I know better that I can handle difficulties"*) (Tedeschi & Calhoun, 1996). It is a self-report measure with each item being rated on a six-point Likert scale with values ranging from 0 (*"I did not experience this change as a result of my crisis"*) to 5 (*"I experienced this change to a very great degree as a result of my crisis"*). The score from each item is totalled to create a 'Total PTG' score, which can range from 0-105. Research has shown the PTGI to have satisfactory internal consistency (α = .90), test-retest reliability (r = .71), and satisfactory concurrent, discriminant and concurrent validity (Tedeschi & Calhoun, 1996).

Three versions of the BFS were used by the included papers. One paper (Mavandadi et al., 2014) used Antoni et al. (2001)'s version of the BFS, which was originally developed for use with people with breast cancer. This version of the BFS has 17-items which assess benefits in a variety of domains, including a developed

awareness of the role of others in their life, an acceptance of the possible difficulties in life, and a redefined sense of purpose. Responses are made on a five-point Likert scale (1 = *"not at all"* to 5 = *"extremely"*). This version of the BFS has acceptable internal reliability (α = .95).

Mohr et al. (1999) developed a 63-item questionnaire to capture how MS impacts psychosocial functioning. Factor analyses were conducted on the scale and revealed three factors; one of which was 'Benefit Finding'. The Benefit Finding factor consisted of 19-items, which were isolated by two of the included studies (Pakenham, 2005, 2007b) and used as an independent measure. The inventory consists of 19 statements (e.g., *'MS has made me appreciate life more'*), which participants are required to rate on a 5-point Likert scale ranging from 1 (*'strongly disagree'*) to 5 (*'strongly agree'*). Mohr et al. (1999) reported good internal consistency (α = .84) of the Benefit Finding subscale. However, it is important to note that the Benefit Finding factor had the lowest reliability of the three factors identified by Mohr et al. This is the only scale referenced within this review which appears to have been validated for people living with a NDC, specifically MS.

Pakenham and Cox (2009) used Mohr et al. (1999)'s 19-item scale, combined with qualitative data gained from their own previous research (Pakenham, 2007b) to trial the 67-item Benefit Finding in MS Scale (BFiMSS). Items consisted of a statement (e.g., *'new opportunities have become available'*), which participants then rated on a 3-point Likert scale (1 *'not at all'* to 3 *'a great deal'*). Following factor analysis, the final version of the BFiMSS contained 43-items, which was found to show good internal reliability (α = .94).

Finally, McBride et al. (2008) used the Silver Lining Questionnaire (SLQ-38) (Sodergren et al., 2002), designed to measure adversarial growth. Participants are asked to read 38 statements and indicate their level of agreement on the same 5-point scale used by Mohr et al. (1999). Sodergren et al. (2002) showed the SLQ-38 to have good internal consistency (α .93) and test-retest reliability (r = .90; p < .001) with participants with respiratory and cardiac conditions.

Factors Associated with PTG

For the purpose of reporting and to simplify the process of categorising the findings, the term PTG will be used consistently here, regardless of whether this was the term used within the original article. Table 4 shows a summary of the key findings from each of the included studies.

Demographic Factors

Five of the included studies analysed the links between various demographic factors and PTG. The demographic variables included varied between studies, however Pakenham (2005), Mohr et al. (1999) and Vescovelli et al. (2020) found no significant relationships between age, gender or marital status and PTG, with Ackroyd et al. (2011) additionally finding no relationship between ethnicity or employment status and experience of PTG. One study found that employed participants reported significantly higher levels of PTG than participants who were unemployed or in receipt of disability benefit (Mohr et al., 1999). Stutts et al. (2020) found older participants and participants who reported having a religion were likely to experience higher levels of PTG. Quantitative studies, or those with a quantitative element, were more likely to investigate a link between various demographic factors and PTG.

Table 4: *Summary of Key Findings*

Author (year)	Methodology	Aims	Findings in Relation to PTG
Mohr et al. (1999)	Mixed	• To better understand how patients with multiple sclerosis view the effects of the disease in their psychological functioning.	• People with MS reported experiencing benefits from their illness. Benefit finding was related to positive reappraisal, seeking social support, anxiety and anger. It was not related to depression, any disease-related factors, or any demographic factors, aside from employment status.
Evers et al. (2001)	Quantitative	• To develop a short, reliable, valid questionnaire for assessing the a priori constructs of helplessness, acceptance, and perceived benefits in patients with chronic diseases.	• Perceived benefits were positively correlated with factors such as 'acceptance', duration of disease, positive mood, extraversion, optimism, an active coping style and a social network. • Perceived benefits were negatively correlated with helplessness, age, number of negative symptoms, negative mood and neuroticism (*).
Pakenham (2005)	Quantitative	• To examine the direct and buffering effects of benefit finding on both positive and negative outcomes after controlling for the effects of relevant demographics and the stress and coping predictors: illness parameters; problem context; and stress appraisal.	• Benefit Finding was divided into two factors: 'Personal Growth' and 'Family Relations Growth'. • Benefit Finding was unrelated to all demographic factors, apart from disease type and time since symptoms onset. • 'Personal Growth' was positively correlated with life satisfaction and positive affect. • 'Family Relations Growth' was negatively correlated with negative affect, and positively correlated with life satisfaction and positive affect.
Pakenham (2007a)	Quantitative	• To examine the adequacy of the BFS as a comprehensive measure of benefit finding in MS. • To further explore the nature of benefit finding in MS.	• People living with MS experience a wide variety of 'benefits'. • Key themes included: 'personal growth'; 'interpersonal benefits'; 'a greater appreciation of life'; 'new opportunities'; 'health and life priorities'; 'goals'; and 'spiritual gains'.
Pakenham (2007b)	Qualitative	• To examine the dimensional structure of a multi-item measure of sense making in people with MS. • To investigate relations between sense making and adjustment (life satisfaction, positive state of mind, anxiety, depression, and caregiver adjustment rating of the care receiver), after controlling for the effects of adjustment assessed 12 months earlier and	• Key themes included: 'redefined life purpose'; 'acceptance'; 'luck'; 'changed values and priorities'; and 'spiritual perspective'.

		the relevant demographic and illness variables.	
McBride et al. (2008)	Quantitative	• To assess the factor structure of the SLQ-38. • Investigate any possible effects of illness type, age or gender differences in reporting positive changes following illness.	• Individuals with MS can experience benefits; however, the level of adversarial growth is less in MS than in conditions such as cancer, renal disease, and cardiac disease.
Pakenham (2008)	Mixed	• Explore the nature of sense making in MS using qualitative data. • Investigate anticipated sense making in individuals who are unable to make sense of their illness. • To examine relationships between sense making and demographics, illness-variables and having a religious-spiritual belief. • To examine relations between sense making and positive (life satisfaction and positive states of mind) and negative (depression and anxiety) adjustment outcomes after controlling for the effects of relevant demographics, illness-variables and religious-spiritual belief.	• Participants who felt able to identify a cause for their illness felt better able to make sense of their condition. • Key categories included: 'acceptance'; 'experienced growth'; and 'spiritual and religious explanations'. • Many saw MS as a prompt to take better care of themselves and make positive interpersonal changes. Others reported finding a new purpose and opportunities.
Pakenham & Cox (2009)	Quantitative	• To examine the dimensional structure of the Benefit Finding in MS Scale. • To investigate the Benefit Finding in MS Scale factors with respect to reliability, retest stability, external and convergent validity and associations with social desirability. • To examine relations between the benefit finding factors and adjustment outcomes across a 12-month interval.	• Seven key benefit finding dimensions emerged: family relations; personal growth; spiritual growth; new opportunities; compassion/empathy; lifestyle gains; and mindfulness. Mindfulness was a new domain that has not emerged in other benefit finding scales.
Mock & Boerner (2010)	Quantitative	• To examine patient-caregiver pairs in the context of ALS, and the association of sense making and benefit finding with number of depressive symptoms.	• The majority of participants reported experiencing benefits as a result of their ALS. • Participants made sense of their condition by learning about ALS, identifying a possible cause and believing in a higher power.
Ackroyd et al. (2011)**	Quantitative	• To investigate whether patients with MS and their partner showed adversarial growth. • To investigate what factors predicted adversarial growth in patients with MS and their partners. • To investigate whether there is a relationship between distress and growth.	• Most participants reported experiencing adversarial growth as a result of their MS. • 'Personal control', number of MS symptoms, and a belief about the cyclical nature of symptoms were all significantly correlated with growth; however, these factors were not significant in final regression analyses.

Mavandadi et al. (2014)**	Quantitative	• To examine the association between perceived benefit finding and marital quality among dyads of individuals with PD and their spouses.	• Participants who perceived their relationship to be of higher quality reported increased levels of benefit finding.
Stutts et al. (2020)	Quantitative	• To describe levels of self-compassion, optimism, and post-traumatic growth in individuals with Parkinson's Disease. • To explore the relationships between positive psychological variables and psychological health. • To examine demographic variables related to positive psychological variables and psychological health.	• Individuals reported experiencing a 'moderate' level of PTG. • Participants experienced the greatest change in the domains of 'appreciation of life', 'relating to others' and 'personal strength'.
Vescovelli et al. (2020)	Mixed	• To investigate PTG in PD patients using both quantitative and qualitative methods.	• Participants in the 'high PTG' group experienced significantly lower levels of anxiety, depression, and irritability-hostility. • Three main themes emerged from the qualitative interviews: 'life philosophy and existential meanings'; 'interpersonal relationships'; and 'body awareness and body connectedness'. Chi-square analysis showed that those participants in the 'high PTG' group were more likely to report the above themes.

* MS results could not be differentiated from RA results

**Only clinical sample data has been reported, partner data has been excluded

Disease-Related & Symptomology Factors

Six of the included studies examined various disease-related and symptomology factors in relation to the experience of PTG. Studies which were purely quantitative in nature were more likely to find a relationship between disease-related factors and PTG. Mohr et al. (1999) found that PTG was not related to length of time since diagnosis, or symptoms related to mobility, continence, fatigue, visual problems, sexual dysfunction, pain or level of neuropsychological functioning. However, these findings appear to juxtapose those of the other five studies. Four studies found a positive relationship between length of time since diagnosis or symptom onset and experience of PTG, therefore suggesting those who have been living with the condition longer may be more likely to report PTG (Evers et al., 2001; Pakenham, 2005, 2008; Pakenham & Cox, 2009). Evers et al. (2001) additionally found a link between fewer physical symptoms and increased PTG; however, their sample consisted of people living with either MS or RA and these results cannot be separated so should be interpreted with caution.

Pakenham (2005) found a link between disease type in MS and likelihood of experiencing PTG, suggesting those with relapse-remitting MS were more likely to report higher levels of PTG than those who had chronic progressive MS; a finding which was supported by Pakenham (2008), who also found that individuals with MS who were able to carry out more activities of daily living reported more PTG.

Ackroyd et al. (2011) found PTG was not associated with any illness-related variable, including type of MS, MS severity, or duration of illness. Nevertheless, PTG was significantly correlated with perceived control over illness and symptoms, number of symptoms and a belief about symptoms occurring in a cycle or pattern which can

be predicted. However, none of these factors emerged as significant predictors in final regression equations.

Mental Health & Psychological Factors

The findings of the included studies lack consistency in determining the role of mental health and psychological factors in the experience of PTG. Six studies examined the role of depression or mood in relation to PTG. Three of these studies found that PTG was negatively correlated with negative mood, and positively correlated with positive mood (Evers et al., 2001; Pakenham, 2005; Vescovelli et al., 2020), suggesting that level of PTG changed in line with variation in mood. The remaining three studies found no link between depression and level of PTG (Mock & Boerner, 2010; Mohr et al., 1999; Stutts et al., 2020). Pakenham (2005) further concluded that PTG is important in supporting positive mental wellbeing but is less important in modulating distress.

Three studies examined the role of anxiety in PTG. Interestingly, Mohr et al. (1999) found PTG to be positively correlated with both anxiety and anger, suggesting those who scored higher on the anxiety and anger factors of the Profile of Mood States (POMS) (McNair et al., 1981) questionnaire are more likely to experience PTG. In contrast, Vescovelli et al. (2020) found higher levels of PTG to be associated with significantly lower anxiety, and Stutts et al. (2020) found no correlation between PTG and anxiety or stress.

PTG was also found to be positively correlated with life satisfaction (Pakenham, 2005), gratitude (Vescovelli et al., 2020), extraversion (Evers et al., 2001) and optimism (Evers et al., 2001; Stutts et al., 2020). Evers et al. (2001) further found PTG

was negatively correlated with ‘neuroticism’ and helplessness. Stutts et al. (2020) found no relationship between PTG and self-compassion.

Interpersonal Coping Factors

Eleven of the included papers reported findings relating to interpersonal factors. Interpersonal factors were reported regardless of methodology used, however, the way this factor was operationalised did appear to differ depending on chosen methodology. For example, studies involving qualitative data were more likely to report on relationships both inside and outside the family, whereas studies involving solely quantitative data typically focussed on family relationships.

Two studies found positive correlations between PTG and social support networks (Evers et al., 2001; Mohr et al., 1999). Pakenham (2005) found PTG to consist of two factors, one of which was the ‘Family Relations Growth’ factor, which described a feeling of being closer to friends and family. This factor was found to be negatively correlated with negative mood, and positively correlated with dyadic adjustment, life satisfaction and positive affect. It was also found to play an important role in sustaining positive psychological states but had less impact on distress regulation. This factor was supported by Pakenham and Cox (2009) who identified seven elements of PTG, one of which was labelled ‘family relations’.

In a later study, Pakenham found participants regarded MS to be a catalyst for interpersonal change. Some participants saw MS as the cause of a relationship (romantic or platonic) breakdown but suggested this had been a positive outcome, while others reported growth and positive change in relationships (Pakenham, 2008).

Pakenham (2007b) asked participants to complete the BFS (Pakenham & Cox, 2009) and found all ‘interpersonal benefits’ to be reported, plus two additional benefits,

which focussed on improved relationships with both professionals and others living with MS.

Vescovelli et al., (2020) conducted qualitative interviews which revealed an 'interpersonal relationships' theme, containing the following sub-themes: 'proximity and support'; 'openness and sharing'; and 'loneliness and isolation'. A subsequent chi-square analysis showed those reporting higher levels of PTG were more likely to identify these themes.

Furthermore, Mock and Boerner (2010) found 65% of those reporting PTG did so in the form of relationships and social ties. Stutts et al. (2020) administered the PTGI to people living with Parkinson's disease and found the most change to be reported in three of the five domains, one which was 'relating to others'. Mavandadi et al. (2014) found participants who scored higher on the Quality of Marriage Index were significantly more likely to report more benefit finding factors on the BFS, suggesting those with higher levels of relationship satisfaction experienced increased levels of PTG.

However, despite the positives reported above, McBride et al. (2008) found people living with MS reported less improvement in their personal relationships than those living with cancer.

Intrapersonal Factors

Pakenham (2008) found those who tended to attribute 'causal explanations' to their MS were more likely to report PTG; these explanations included identifying a genetic/biomedical, psychosocial or environmental cause. The importance of identifying a cause for their condition was supported by Mock and Boerner (2010) who found that 20% of participants experienced PTG by identifying a possible cause and

60% made sense of their condition by learning more about it. Other coping strategies identified were positive reappraisal (Mohr et al., 1999), learning about the condition (Mock & Boerner, 2010), and feeling a sense of control over the condition (Ackroyd et al., 2011; Pakenham, 2007b).

Five studies reported the positive role of 'acceptance' in PTG (Evers et al., 2001; Pakenham, 2007a; Pakenham, 2007b; Pakenham, 2008; Vescovelli et al., 2020), suggesting those who were better able to accept the condition experienced heightened levels of PTG. Evers et al. (2001) also identified a weak negative correlation between helplessness and PTG.

Pakenham (2008) recognised an 'Experienced Growth' category which captured participants' greater self-awareness. He also highlighted that some participants saw MS as motivation to change their lifestyle in healthier ways, including engaging in self-care, making healthier diet choices and increasing exercise. Others identified MS as providing a new purpose in life, including new goals and opportunities (e.g., career changes). These findings are supported by Pakenham and Cox (2009) who identified personal growth, new opportunities and lifestyle gains as contributing to PTG.

Vescovelli et al. (2020) found three main themes from qualitative interviews, two of these were labelled: 'life philosophy and existential meanings' and 'body awareness and connectedness'. Within the 'life philosophy and existential meanings' theme, six sub-themes were identified, including personal growth, appreciation of life, new possibilities, spirituality, gratitude and altruism. Three sub-themes were associated with 'body awareness and connectedness': 'pain, mood and negative emotions'; 'personal strengths, autonomy and mastery'; and 'proactive style and care

of self'. Further chi-square analysis showed those participants in the 'high PTG' group were more likely to report these themes.

Perceived life satisfaction and its relationship with PTG was examined by two of the included studies (Pakenham, 2005; Stutts et al., 2020). Pakenham (2005) found the 'personal growth' factor of PTG was positively correlated with life satisfaction. Stutts et al. (2020) found participants reported the most change on the PTGI domains of 'appreciation of life' and 'personal strength', and the least change in the 'new possibilities' domain.

Intrapersonal factors were reported regardless of methodology used. There was no consistency between the intrapersonal factors under investigation across studies.

Spiritual Factors

Ackroyd et al. (2011) and Stutts et al. (2020) found a link between religion and PTG, noting those who identified as belonging to a religious group were more likely to experience higher levels of PTG.

Seven studies made reference to spiritual factors with varied findings. Pakenham (2008) conducted qualitative interviews with people living with MS and 'spiritual and religious experiences' was identified as a theme. Within this theme, participants described seeing their MS as a test of their spiritual or religious faith, as part of God's plan, being 'chosen' and regarded it as being their 'destiny'. Some participants also reported experiencing an increase in their faith or spiritual beliefs post-diagnosis. Pakenham went on to report a significant association between these religious and spiritual beliefs and PTG. This finding is consistent with some of Pakenham's other findings (Pakenham, 2007b; Pakenham & Cox, 2009), however

inconsistent with Pakenham (2007a) who found ‘spiritual perspective’ to be unrelated to PTG and level of adjustment.

Additionally, Mock and Boerner (2010) found 20% of participants reported having a belief system or made reference to a ‘higher power’ which had enabled them to make sense of their diagnosis. Vecovelli et al. (2020) identified three main themes during qualitative interviews, with one of these themes being labelled as ‘life philosophy and existential meanings’, which contained ‘spirituality’ as a sub-theme. It was also found that those who scored higher on the PTGI were more likely to reference these themes during their qualitative interviews (Vescovelli et al., 2020).

Spirituality was a factor which was found in both quantitative and qualitative papers, however the way it was described differed between the two methodologies. For example, within papers where qualitative methods were used, the word ‘spirituality’ was rarely referenced, and instead terminology such as, ‘higher power’ and ‘destiny’ were used. This may be as a result of qualitative papers gaining richer data which enabled them to create categories based on the language used by participants, whereas quantitative studies were more likely to have used language based on factors identified by the measures used.

Discussion

The review systematically examined the current literature exploring how PTG is experienced in NDCs, and the factors associated with it. It was found that PTG is possible for those living with a NDC, however the factors influencing it appear to be inconsistent.

The included studies differed greatly in their aims, operationalisation of variables and key terms, designs and methodological approaches. This not only made comparison complex, but also precluded other methods of systematic review, such as meta-analysis and thematic synthesis, which should be taken into consideration when interpreting the results. It does, however, accurately reflect the current position of PTG in relation to NDCs and highlights the importance of exploring the area further in a more robust and consistent fashion.

This review identified that many of the findings between the included studies are conflicting and few definitive trends emerged. There are a number of potential reasons for this, including the varying degrees of quality between the studies, and the diversity in methodological design, sample, measures and the way PTG was operationalised.

Five studies analysed the relationship between age and experience of PTG, but only one found an association. Stutts et al. (2020) concluded those living with Parkinson's disease were more likely to experience PTG if they were older; a finding which juxtaposes much of the previous research. A meta-analysis and two systematic reviews have previously explored PTG across a range of contexts and identified younger individuals as being more likely to experience PTG (Barskova & Oesterreich, 2009; Helgeson et al., 2006; Linley & Joseph, 2004). However, in contrast Boyle et al. (2017) studied the role of age on PTG in those having survived breast cancer. They

suggested that altruism, empathy, and prosocial behaviour are traits which increase with age, and therefore may contribute to a heightened sense of PTG. For example, they suggest that altruistic coping styles, such as supporting others living with cancer, and providing care to younger family members, are strategies which may be more prevalent within the older population and may play an important role in enhancing the experience of growth. More longitudinal research is therefore needed to fully explore the impact of age on PTG in NDCs and more generally.

Most of the studies which examined the role of duration of condition found that PTG was more likely to be reported by those living with the condition for longer. Barskova and Oesterreich (2009) suggested that PTG requires a significant length of time to pass for individuals to fully process the trauma and identify their growth. The inconsistent nature of the findings reported here in relation to length of time and experience of PTG is consistent with previous systematic reviews (Barskova & Oesterreich, 2009; Linley & Joseph, 2004). Two meta-analyses have previously identified time since traumatic event as a potential moderating factor between PTG and psychological adjustment; suggesting that as time passes the relationship between PTG and psychological wellbeing may become stronger (Helgeson et al., 2006; Sawyer et al., 2010). This is an area which would benefit from further research, using a longitudinal design, to aid clinical understanding of the trajectories of PTG.

The findings related to symptomology as a factor in PTG were also inconsistent. Three studies reported findings which could suggest that those who experience fewer physical symptoms are more likely to experience PTG (Evers et al., 2001; Pakenham, 2005, 2008). Pakenham (2005) found that those with relapse-remitting MS were more likely to experience growth than those with chronic progressive MS, suggesting those who experience acute attacks of symptoms with periods of inactivity experience

higher levels of growth than do those who experience more of a progressive symptomology. These findings are consistent with previous research which has shown a number of physical symptoms, including motor function (Weintraub et al., 2006) and pain and fatigue (Berzins et al., 2017; Bombardier et al., 2010; Widerström-Noga & Finlayson, 2010), to be related to psychological factors, such as depression, which may ultimately impact an individual's likelihood to experience PTG.

Ackroyd et al. (2011) found a significant positive correlation between level of growth and perceived manageability of condition, suggesting those who found their condition to be more manageable experienced increased levels of growth. This is consistent with previous research which has suggested that an individual's ability to cope with and appraise difficult life events is influenced by how manageable they believe the event to be (Kennedy et al., 2009). This may therefore suggest potential differences in the way PTG is experienced across different NDCs due to the differences in the way they impact functioning and potentially perceived manageability. These associations would benefit from further longitudinal exploration as it is a factor which is likely to change over time due to the progressive nature of NDCs.

The findings relating to psychological and mental health factors, including depression and anxiety, and their role in the experience of PTG are inconsistent. This is possibly due to differences in sample, design, and the way in which these variables are operationalised and measured. Previous systematic reviews have not found a relationship between depression and PTG, or if they do, it is generally negatively related, suggesting that as level of depression increases, the likelihood of experiencing growth decreases (Helgeson et al., 2006; Linley & Joseph, 2004; Pascoe & Edvardsson, 2013). Three studies analysed the role of anxiety in the experience of PTG with mixed results (Mohr et al., 1999; Stutts et al., 2020; Vescovelli et al., 2020),

which is consistent with previous systematic reviews (Pascoe & Edvardsson, 2013). Ovaska-Stafford et al. (2021) highlights the importance of remembering that a diagnosis of a NDC does not automatically result in the person experiencing psychological distress, and previous research has highlighted no significant psychological distress amongst certain NDC populations (Rabkin et al., 2005). Furthermore, two studies acknowledged a positive relationship between optimism and PTG (Evers et al., 2001; Stutts et al., 2020), which is consistent with previous research conducted with different sample groups (Smith & Zautra, 2008; Tusaie & Dyer, 2004).

The included studies acknowledged the importance of interpersonal factors in the experience of PTG. Social support and having someone who can share the challenges of the illness, has been found to play an important role in positive adjustment in both those living with a long-term illness and their carers (McCabe et al., 2004; Pakenham, 1999; Wilks & Croom, 2008) (Shapiro, 2002). Vitali (2010) conducted a review into the role of resilience in coping with MS and found social support to be key factor underpinning an individual's ability to function with MS. It can be argued that those with NDCs are at greater risk of being socially isolated due to cognitive difficulties, behavioural changes and mental health problems. Although resilience is a different construct to PTG, it highlights the importance of social connectedness being integrated into the NDC care pathway (Ovaska-Stafford et al., 2021). McCabe et al. (2004) acknowledged that those with NDCs are limited in being able to access social support and found that this was associated with poorer psychological adjustment in MS.

A systematic review examining PTG in several serious medical conditions (Barskova & Oesterreich, 2009) identified two coping responses: acceptance and resignation. Those who were able to accept their condition experienced higher levels

of PTG than those who had resigned themselves to the condition. This is consistent with previous literature documenting the importance of acceptance in PTG and in coping more generally (Armeli et al., 2001; Park et al., 1996).

Findings related to spirituality and its role in PTG were inconsistent. Those studies where tools were used which specifically investigate spirituality, such as the PTGI, were more likely to report this as a factor. These findings support a previous systematic review which found that religion and spirituality can often, but not always, be beneficial in the aftermath of a trauma (Shaw et al., 2005).

Limitations of the Included Studies

It is important to acknowledge the included studies are not without their individual limitations, as can be seen by the results of the quality assessment (see Table 2). One such limitation was the way in which PTG was measured. Only one of the measures used by the studies had been validated for use with a clinical sample of people living with a NDC (Pakenham). Therefore, it cannot be known whether the other tools used are a valid measure of PTG in NDCs.

Additionally, many of the samples included in the studies were limited. Many studies recruited modest samples from one clinic location which raises questions about the generalisability of findings. Studies completed by Pakenham had the largest and potentially most representative samples, however participants were all based in Australia and so findings may not be generalisable to other countries, especially those countries with different healthcare models. It is also important to note that studies completed by Pakenham often used the same sample and this may therefore have skewed some of the findings reported above.

Many of the included studies were cross-sectional in nature with a variety of measures used to explore PTG and related terms. This may therefore inhibit our

understanding of how PTG develops over time, which is important to explore further as it links to Tedeschi and Calhoun (1996)'s belief that PTG is not just a single outcome of an event, but a process which occurs over time.

A further limitation of the current review relates to how PTG is described and operationalised by the included studies. Due to the limited literature surrounding PTG in NDCs, search terms were expanded to include terms typically believed to be related to PTG, as identified by previously conducted systematic reviews (Barskova & Oesterreich, 2009; Gemson et al., 2018). It is important to recognise that although these terms are related, they may be fundamentally different from PTG in a number of ways. Tedeschi et al. (2018) advised caution when drawing parallels between findings related to PTG and other concepts, such as 'perceived benefits' and 'benefit finding', because they do not always capture the transformative experiences in the same way PTG does. The current review attempted to mitigate this limitation by including research which had defined PTG or the related term in a way which captured the person's psychological growth from pre- to post-diagnosis of their NDC. As a result, literature which used the included search terms but only reported a return to baseline or a sense-making experience without growth or development, were excluded from this review. It is, however, important to recognise that this lack of consistency in terms used made drawing comparisons between the studies difficult and may explain the inconsistency in many of the findings, given that they may have been exploring different phenomena. Future studies should aim for consistency in the way this construct is operationalised and measured to ensure meaningful comparisons can be made.

Limitations of the Review

Despite including several NDCs during the systematic searches, MS was heavily represented within this review. This highlights the sparsity of research around growth in those living with other NDCs. It is worth noting that the systematic searches produced several studies which related to growth in carers and family members of those living with NDCs, such as Alzheimer's and dementia (Berberena, 2017; Butcher et al., 2016), Parkinson's disease (Greenwell et al., 2015; McLaughlin et al., 2011), ALS/MND (Aoun et al., 2012; Boerner & Mock, 2012), MS (Diaz, 2016; Kim et al., 2020) and Huntington's Disease (Aubeeluck et al., 2012; Kavanaugh et al., 2015) which raises the question as to why those living with these conditions are often excluded from samples. There are many reasons why studies focussing on MS samples may be over-represented in the literature; one such reason may be the age of onset, as those diagnosed with MS tend to be diagnosed at a younger age compared to those living with other NDCs. This earlier age of onset may mean people living with MS are easier to recruit for certain studies (i.e., those recruiting through social media or other web-based recruitment strategies). Additionally, MS is believed to have less cognitive symptomology compared to other NDCs (Osaka-Stafford et al.), which also means they may be an easier sample to access, recruit and research, than samples who may display more significant cognitive difficulties.

Furthermore, it is important to acknowledge that although the NDCs included within this review share many commonalities, such as them being degenerative, and having symptoms which impact physical functioning, cognition, and emotional wellbeing, they do also of course have several significant differences. For example, age of onset, rate of decline, and specifically symptomology not only varies between each condition, but also within each condition as well. With this in mind, it is important

to recognise that findings from MS samples cannot be generalised to other NDC, and therefore more research into other NDCs is needed.

Finally, it is important to acknowledge the limited number of quality assessment tools available to evaluate mixed methods research. Initially, the Mixed Methods Assessment tool (MMAT) (Hong et al., 2018) was used to quality assess the included studies. However, it was felt to be limited in its evaluation criteria and previous studies have found it to have inconsistent interrater reliability and content validity (Hong et al., 2018). Therefore, alternatively quality assessment tools were sought. The Quality Appraisal for Diverse Design (QuADS) (Harrison et al., 2021) was also considered, however a copy of the tool was unable to be located. Therefore, the QATSDD was chosen due to its flexibility and ease of use (Sirriyeh et al., 2011).

Clinical Implications

The key clinical implication from this review is that PTG is possible for those diagnosed with a NDC, however the factors contributing to the experience are inconsistent. It is therefore important that we understand the factors so we can help promote PTG as far as possible. Being aware that PTG is possible may instil hope in those diagnosed and their families, however, conversations around this should always be approached with caution. The individualistic nature of the experience makes this a complex concept, and it is important to note that not everyone with a NDC may see growth as a priority. It is therefore important for clinicians to approach the topic of PTG sensitively so as not to invalidate any difficult emotions that may be being experienced. One way this may be done sensitively is by professionals using compassionate, non-judgemental, language which provides a variety of options and responses to a traumatic event.

Findings of this review suggest interventions which focus on improving quality of life and psychological wellbeing may be helpful in amplifying the experience of PTG in people living with NDCs. Previous meta-analyses have identified the effectiveness of CBT for trauma (Roepke, 2015) and mindfulness-based interventions (Li et al., 2020) in heightening the experience of PTG in different sample groups. Additionally, Simpson et al. (2021) highlighted the role interventions such as Acceptance and Commitment therapy (ACT) may play in amplifying the experience of PTG in people living with NDCs. This supports Simpson et al. (2021)'s recommendation that interventions which aim to build resilience may increase the psychological wellbeing of people living with NDCs. Additionally, specific interventions which tackle symptoms of depression and anxiety may be helpful on a more individualised basis, but these experiences appear to be inconsistent (Simpson et al., 2021).

Findings have also highlighted the importance of having a strong support network. Third sector services may be in a better position to facilitate peer support than NHS services and it is important for links between these services to be built to ensure more holistic models of care.

Conclusion

This review has highlighted that PTG following a diagnosis of a NDC is a valid concept. Six factors were identified as being important in the experience of PTG in those living with NDCs. These factors included, demographic factors, disease-related and symptom factors, mental health and psychological factors, interpersonal factors, intrapersonal factors, and spirituality factors. However, the exact factors related to the experience of PTG were shown to be inconsistent across the included studies, which could be a result of the noted limitations or simply because PTG is widely

acknowledged as being an individualistic experience. The findings point to important clinical implications. It highlights the importance of clinicians recognising that PTG is possible in NDCs, the importance of identifying factors that may promote PTG, and suggesting potentially helpful interventions to aid in this process. Further research is needed, especially longitudinal research, which would be better able to 'map' trajectories of PTG over time, greatly expanding our understanding of this experience. It is also important for future research to consistently operationalise PTG so that comparisons can be easily drawn in future research.

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CHAPTER 2: EMPIRICAL PAPER

The Experience of Post-Traumatic Growth in People Living with Dementia: A Grounded Theory Study

Charlotte Cooper

Prepared in accordance with guidelines for submission to Dementia

Abstract

Discourses around living with dementia are typically negative and centre around concepts such as loss, impairment and fear. However, there is a growing body of literature that suggests that many individuals can not only live a positive and fulfilling life with dementia but may grow in a way that allows them to develop beyond the person they were before the diagnosis. Post-traumatic growth (PTG) is a term used to describe the positive transformation which can occur following a traumatic or challenging event, and it has been applied to several health conditions. The current research aims to explore and understand people's experiences of living with dementia in the context of PTG. Grounded theory methodology was used to create a theoretical framework based on semi-structured interviews with nine people living with dementia. The theoretical model highlighted the importance of peer support, meaningful activity and creating a new narrative for themselves, their lives and their dementia. The model also captured the belief amongst people living with dementia that these factors slow down the progression of the disease and counter many of the fears that come along with living with dementia. It is important for clinicians and services to recognise that PTG in dementia is possible and to be aware of factors that may help to increase the likelihood of someone experiencing PTG following their diagnosis.

Introduction

Dementia is an umbrella term used to describe over 100 different neurodegenerative conditions that impact an individual's cognition, emotions and behaviours. It is estimated there are currently 850,000 people in the UK living with dementia; this figure is expected to rise to over 1 million by 2025, and over 2 million by 2050 (Alzheimer's Society, 2017). It is expected this will have a significant impact on the NHS and other services who support people living with dementia.

Discourses around dementia typically revolve around negative concepts such as fear (Moniz-Cook et al., 2006), stigma (Moniz-Cook. & Manthorpe, 2009), loss, suffering and decline (Mitchell, Dupuis, et al., 2013). Outside of academic literature, there is growing evidence to suggest many individuals continue to live a positive and fulfilling life despite their dementia (Alzheimer's Society, 2017; Bryden, 2005; Mitchell, 2018b; Phinney, 2008). However, it is an area that has been largely under-researched academically (Wolverson et al., 2016).

These negative discourses may have resulted in research neglecting to investigate or recognise growth of any kind in people living with dementia, with positive experiences often regarded as resulting from a lack of awareness (Steeman et al., 2007). The conceptual framework of Positive Psychology (Seligman, 2002) may help in shifting the discourse of dementia to a more positive and person-centred stance. Positive Psychology can be defined as the study of constructs and processes that underwrite our ability to function happily and optimally at individual, systemic and societal levels. Several constructs related to Positive Psychology have already been applied to dementia, including hope, optimism and personal growth (Duggleby et al., 2009; Wolverson et al., 2010).

‘Growth’ has been recognised as a complex concept which is a subjective experience and is therefore difficult to define (Patterson & Wolverson, 2016). However, it is broadly acknowledged as a *“positive change in our psychological functioning in which we develop beyond a previous version of ourselves”* (Patterson & Wolverson, 2016, p. 153). The notion of personal growth in dementia suggests people might not just live well *in spite* of dementia, but *because* of it (Wolverson et al., 2016). Research around growth in dementia has shown that, after diagnosis, people employ effective coping strategies (Pearce et al., 2002) and sustain positive relationships (Harris, 2013) and hope (Wolverson et al., 2010). It is a concept which has also been studied in relation to ageing (Linley et al., 2004), various traumatic experiences (Tedeschi et al., 2018) and living with chronic illness (Paterson, 2001).

In 2009, the Department of Health (DoH) published their Best Practice Guidance which introduced the notion of people being able to ‘live well’ with dementia (Department of Health, 2009). This guidance does not offer a clear definition of what is meant by ‘living well’ with dementia. The DoH do, however, state the aim of the guidance is to improve the quality of life of people living with dementia by increasing knowledge and understanding and reducing stigma, ensuring earlier diagnosis and intervention, and developing services to better meet the needs of people living with dementia (Department of Health, 2009). Personal growth may be one way of understanding how some people live well with dementia.

However, in recent years, the term ‘living well’ has been the subject of debate amongst people living with dementia (Mitchell, 2015, 2018a; Rahman, 2019), with many feeling it presents an overly optimistic view of dementia and fails to recognise how traumatic it can be for some (Aminzadeh et al., 2007; Steeman et al., 2006; Werezak & Stewart, 2009). When we experience something as traumatic, it can

challenge and shatter our assumptions and beliefs about the world. It is thought some people can be positively transformed through the process of restructuring these beliefs and assumptions (Tedeschi & Calhoun, 2004); a phenomenon described as post-traumatic growth (PTG) (Tedeschi & Calhoun, 1996).

Many different terms have been used to describe this, and similar, experiences, including 'benefit finding', 'meaning making', 'sense making' and 'growth'. However, in recent years, the term PTG has increased in popularity within both clinical and research settings (Joseph & Linley, 2008). Additionally, it is important to highlight the differences between PTG and other positive psychological traits often associated with challenging life events, such as resilience. When discussing resilience, terms such as 'recover', 'bounce-back' and 'adjust' are often used, which all suggest a return to an individual's baseline functioning. PTG differs in its assumption that individuals do not just return to baseline, but positively grow beyond who they were before the trauma (Tedeschi & Calhoun, 2004).

The experience of PTG is thought to be individualistic. However, it is broadly accepted that the experience can be divided into five domains: relating to others; new possibilities; personal strength; spiritual change; and appreciation of life; therefore, highlighting that PTG encompasses inter- and intra-personal growth, in addition to existential growth (Tedeschi et al., 2018). Tedeschi and Calhoun (1996) described the experience of PTG as being both a process and an outcome, depending on where the individual is at in their trauma journey at the time. Regardless of whether PTG is seen as a process or an outcome, Tedeschi et al. (2018) highlighted that it often co-occurs alongside the process, suggesting that PTG is not a standalone experience, but rather one that runs parallel with the highly challenging life experiences which have prompted the person's growth.

There is evidence to suggest that being diagnosed with, and living with, dementia can be traumatic (Aminzadeh et al., 2007; Steeman et al., 2006; Werezak & Stewart, 2009) and devastating for some (Clare, 2003; Henderson, 2002; Holst & Hallberg, 2003; Phinney & Chesla, 2003; Steeman et al., 2007; Van Dijkhuizen et al., 2006). The definition of PTG has been expanded to include 'challenging events' (Tedeschi et al., 2018), and therefore regardless of whether people experience dementia as traumatic or not, there is a need to investigate the potential experiences of PTG in dementia in the same way as other physical health conditions such as stroke (Gangstad et al., 2009), cancer (Stanton et al., 2006), traumatic brain injury (Powell et al., 2007; Powell et al., 2012) and multiple sclerosis (Mohr et al., 1999; Pakenham, 2007b, Cooper et al., 2021).

As a result, it is therefore possible that dementia itself could stimulate PTG in some individuals. A variety of terms have previously been used to conceptualise growth following dementia diagnosis (e.g., 'growth', 'personal growth', 'positive growth' etc.). However, empirical evidence is yet to embed the experience of living with dementia within a trauma framework. Therefore, the concept of PTG is yet to be applied to people living with dementia.

The aim of the current research is to investigate whether people living with dementia experience PTG, and if so, what does this experience look like, what factors are involved, and how does this model of PTG differ from other models with other clinical samples. Given the limited previous research in the area and the variation in the way growth and PTG has been conceptualised and measured, a qualitative approach utilising grounded theory was chosen to construct a generalisable theoretical model, which can later be tested with larger groups across multiple settings.

Method

Ethical Approval

Ethical approval was sought, and favourable opinion given by the NHS Research Ethics Committee and Health Research Authority (see Appendices 7 and 8). The University of Liverpool acted as sponsor for the research.

Design and Qualitative Methodology

Grounded theory allows for the development of theory based on categories that are constructed whilst creating meaning from the data (Willig, 2008). It was deemed to be an appropriate framework to address the research aim, which ultimately seeks out the meaning and understanding participants have made of their experiences of living with dementia in the context of PTG. Additionally, grounded theory involves the recruitment of a heterogeneous sample which allows for a range of experiences and perspectives to be captured and integrated into a universal diagrammatic and narrative model (Willig, 2008). This is in juxtaposition to other qualitative approaches, such as Interpretative Phenomenological Analysis (IPA), which seeks to recruit a homogenous sample with the aim of identifying similarities and differences within the sample group (Smith et al., 2009).

Constructivist grounded theory (Charmaz, 1990, 2000, 2006) is believed to be a hybrid form of constructionism, grounded theory and pragmatism. It differs from other positivist grounded theory approaches (Glaser & Strauss, 1967; Strauss & Corbin, 1994, 1998), due to its acknowledgement that the social world is complex and contains multiple and varied perspectives and experiences (Appleton & King, 2002). Constructivist grounded theory views research as being a mutual and collaborative process between researcher and participant, whereby the participant's personal

experience and expertise of living with dementia and the researcher's personal and professional experiences and understanding of the existing literature can be combined to form a meaningful grounded theory model (Charmaz, 2006). Thus, constructivist grounded theory was chosen as it was felt it allowed people living with dementia to fully embrace their 'expert by experience' role and empowered a group of people who are often dispossessed of their narrative and placed in a powerless position (Baldwin, 2006).

Sample: Size, Strategy and Characteristics

Theoretical sampling is often employed in grounded theory research (Charmaz, 2000, 2006), which describes the process of actively seeking out participants with varied views and experiences which add to the developing theory. Theoretical sampling is informed by a process of simultaneously collecting, analysing and coding data (Charmaz, 2006). This process enables a theory to be developed by directing the researcher to what data needs to be collected (Glaser & Strauss, 1967). Participants are recruited until theoretical saturation is reached; that is, the point at which no new categories are constructed from the data and the existing data is thought to adequately represent the complete range of constructs (Tie et al., 2019). For the present research, a total of nine participants were recruited; the aim was to continue recruitment until theoretical saturation had been reached, however, this was difficult given the time constraints of the DClin and the barriers in place because of the COVID-19 pandemic. The pandemic resulted in the study having to undergo significant amendments through ethics, which reduced the length of time we had to complete the research. Participant demographic information can be seen in Table 5 below.

Table 5: *Participant Demographic Information*

Participant #	Gender	Age (Years)	Type of Dementia	Age at Diagnosis (Years)	Years since Diagnosis (Years)	English as First Language? (Y/N)
1	Male	67	Alzheimer's (Young-Onset)†	58	9	Y
2	Male	68	Alzheimer's (Young-Onset)†	62	6	Y
3	Male	57	Alzheimer's (Young-Onset)†	55	2	Y
4	Male	62	Posterior Cortical Atrophy (PCA)*	58	4	Y
5	Female	67	Mixed (Alzheimer's / Vascular)**	59	8	Y
6	Male	77	Alzheimer's (Young-Onset)†	61	16	Y
7	Male	66	Alzheimer's (Young-Onset)†	64	2	Y
8	Female	65	Mixed (Alzheimer's / Vascular)**	58	7	Y
9	Female	58	Sub-Type Unknown	54	4	Y

† Young-Onset at the point of diagnosis
*original diagnosis of Frontotemporal Dementia given
**original diagnosis of Young-Onset Alzheimer's given

Grounded theory research places a focus on gathering heterogeneous perspectives regarding the construct under investigation (Charmaz, 2006); as a result, broad inclusion and exclusion criteria were employed (see Table 6). Participants' capacity and cognitive abilities were assessed by the referring clinician for those recruited through the NHS and by the research for those recruited through the Dementia Engagement and Empowerment Project (DEEP). DEEP is a UK-based third sector organisation which aims to connect people living with dementia to each other and their local communities. Capacity was monitored throughout the interview process and the researcher would re-assess capacity if required.

Table 6: *Inclusion and Exclusion Criteria*

Inclusion Criteria	Exclusion Criteria
English as first language	Comorbid physical health condition which prevented them from sitting comfortably during the interview
Diagnosis of dementia of which they are aware	
Been living with dementia diagnosis for at least 6 months	
Have the capacity to consent	
Have the cognitive capabilities to engage with the interview	

The research advert was circulated to Clinicians working within the Older Adult Community Mental Health teams within the recruiting NHS Trust (see Appendix 9). It was further advertised on The UK Network of Dementia Voices (DEEP) website and through the DEEP Twitter feed (see Appendix 10). Participants registered their interest in the research by contacting the researcher by email or phone. The researcher responded, providing a brief description of the research and a copy of the Participant

Information Sheet (PIS; see Appendix 11). Participants were asked to read the PIS and were given the opportunity to ask any questions before they consented to take part. Once the PIS had been read, participants who were agreeing to be involved were booked in for a Zoom or telephone interview, depending on their preference. Face-to-face interviews were unable to take place due to the COVID-19 pandemic.

Interviews

Semi-structured interviews took place between October 2020 and April 2021 and were coded and transcribed as they were completed. Interviews were between 60 and 90 minutes in length, and a semi-structured interview schedule (see Appendix 13) was used to guide the conversation. The interview schedule was developed in consultation with research supervisors, both of whom have considerable clinical and research experience of working with people living with dementia. The schedule included the following topics: experience of diagnosis; the impact of the diagnosis on themselves and others; initial thoughts and feelings around the diagnosis and how this compares to now; coping strategies; life changes; opinions on the term 'living well'; and lessons learnt. The interview schedule was adapted after the fifth interview had been coded, to further explore relationships between emerging themes and allow refinement of the model. At the end of their interviews, the final two participants were shown the diagrammatic model and provided with a narrative explanation to test the validity of the model against their experiences. They were also offered the opportunity to provide feedback, which resulted in the wordings of two categories being altered.

The audio from the interviews was recorded using an encrypted iPad provided by the University of Liverpool so they could be transcribed at a later date. Prior to the interview starting, participants were offered a further opportunity to ask any questions

and gave verbal consent which was audio recorded; this was felt to be appropriate due to the difficulties in gaining written consent from participants virtually (see Appendix 12). Once consented, demographic data was collected regarding the gender and age of the participant, type of dementia and age at which they were diagnosed. The researcher transcribed four of the interviews (interviews 1, 2, 8 and 9) to gain an in-depth and immersive view of the data. The remaining five interviews were transcribed by a professional university transcriber and were quality checked by the researcher.

Ethical Considerations

Whilst it was believed minimal risk was associated with taking part in the research, it was acknowledged that discussing their experiences of living with dementia could be emotional for some. Participants were advised the researcher was a Clinical Psychologist in training who is experienced in managing distress. Participants were informed that should they become distressed during the interview, they would be given the opportunity to take a break or withdraw if they wished. No distress was observed or reported by any participant during the research process.

Data was kept confidential unless risk to self or others was disclosed. All identifiable information was removed during transcription to ensure anonymity, and any direct quotations used within this report have been anonymised and pseudonyms used. Transcripts were stored securely on a password protected University server.

Expert-by-Experience Consultation

The Liverpool Expert by Experience group were consulted early during the initial planning of the research. The study documents were reviewed by a group of

people living with dementia, and changes were made to the design and language of these documents prior to submission to ethics. At the end of the interviews, participants were asked for their opinions on how they would like the findings of the research to be fed back to them. As a result, a feedback session is planned for September 2021 and a feedback letter has been sent to all participants in the interim (see Appendix 17).

Analysis

Data analysis followed the steps outlined by Charmaz (2006).

1. In-depth reading of the transcripts and detailed examination of the data, focussing on possible meanings. Narrative and diagrammatic summaries were produced following each interview (see example in Appendix 16).
2. Line-by-line coding was completed.
3. Common codes were then transformed into more focused coding. Focussed coding helps to synthesise large sets of data.
4. Focussed codes then became tentative theoretical categories which were tested against the data.
5. Codes which carried a significant 'weight' of data were made into theoretical categories.
6. Memos were written to capture links between codes and themes.

Quality Assurance

Elliott et al. (1999) presented guidelines for reviewing and assessing the quality of both quantitative and qualitative research. The guidelines for qualitative research

and how these were adhered to during the current research can be seen in Table 7 below.

Table 7: *Quality Assurance Table*

Guideline	Adherence to Guideline

Owning one's perspective: Outlining the position of the researcher, including identifying personal, professional, theoretical and methodological orientations.	• The researcher is a 29-year-old White British female, currently training to become a Clinical Psychologist. She has experience of working with a wide range of client groups, including people living with dementia. She has both a personal and professional interest in the concept of PTG within different contexts.
	• Throughout the research process, the researcher kept a reflective diary to monitor and acknowledge the impact of her personal and professional experiences on the emerging data. Themes included:
	  ○ Initial scepticism about the presence of PTG in dementia.
	  ○ An existing acknowledgement of the limited service provision for people living with dementia and a wondering about the impact this may have on people's experiences.
	  ○ Acknowledgement of the power and privilege of the researcher and especially how their role as both clinician and researcher may impact some participants' reporting.
	• Supervisors have vast amounts of clinical and research experience in working with people living with dementia.
	• As guided by the methodology, the researcher took a social constructivist position (Charmaz, 2006).

Situating the sample: Describing the characteristics of the sample and their life circumstances.	• Demographic characteristics of each participant are shown in Table 1. • Following each interview, the researcher composed a narrative summary, including reflections on the interview process (Appendix 14).
Grounding in examples: Multiple examples of themes are provided in a way which enables readers to understand how the researcher has developed that theme, but also	• Researcher transcribed four of the nine interviews to ensure a thorough understanding of the emerging data. • Line-by-line coding was completed to enable a closeness to the data.

allows readers to derive their own understanding and meaning.	• The final codes and model include direct quotations from the participants. • Participant quotes are embedded within the results section to aid understanding of the themes. • Themes are described thoroughly, narratively as well as diagrammatically, to allow readers to interpret the theme themselves.
Providing credibility checks: The integrity of the data is checked by clarifying the understanding with original participants, employing multiple qualitative reviewers, comparing two or more qualitative perspectives, or by triangulating with quantitative data.	• The researcher kept a reflective research diary, enabling them to acknowledge their interaction with the data (see Appendix 15). • Research supervision enabled the wider research team to review transcripts and code some of the data independently of the main researcher. • During the final two interviews, the researcher invited feedback from the participants on the emerging model to establish whether this fit with their experience. • The model was explored with an independent consultant with significant experience of working with people living with dementia to determine whether this fit with their conceptualisation of construct.
Coherence: The researcher's conceptualisation of the data fits together to form a clear narrative, 'map' or framework of the construct under investigation.	• Narrative and visual summaries of the data, and how the themes relate to one another, are presented in the results section. • Examples of coding categories are provided in Appendix 16.
Accomplishing general vs. specific research tasks: The researcher is clear on the generalisability and reliability of their findings, and on whether they were seeking to obtain heterogeneous or homogenous viewpoints and why.	• The aim was to recruit a heterogeneous sample of people living with dementia. • The limitations of the sample are clearly outlined in the discussion section.
Resonating with readers: The manuscript is written in a way which readers feel accurately reflects the construct under investigation and has clarified or expanded their understanding.	• Narrative and visual summaries of the codes and categories have included direct quotations from participants. • The manuscript has been reviewed by both supervisors and an independent reviewer, feedback has been received and where necessary, amendments have been made.

Reflexivity and Memo Writing

Reflexivity, which can be defined as the researcher's ability to examine their own theoretical stance, values, and roles in the research process so any bias can be explicitly identified, is fundamental in grounded theory research (Charmaz, 2006). The researcher endeavoured to remain reflexive throughout the process, considering their position in relation to the participants, with reference to factors such as culture, class, race, gender, age, sexual orientation, and experience (Wilkinson & Kitzinger, 1996).

Throughout the research process, the researcher kept reflective notes and memos to limit imposing any pre-existing assumptions they may hold as a result of their own experiences, onto the research process and the data. The researcher engaged in regular supervision with both the primary and secondary supervisors, which provided the opportunity for reflection on the emerging data and any pre-existing assumptions or experiences which may have influenced analysis.

Results

Figure 2 is a visual representation of the research findings, describing the process and development of PTG in dementia. Each category was developed through a process of focussed coding and is supported by participant quotes. The model tracks participant's experiences from the 'trauma' of diagnosis, and maps the experience of PTG as it develops.

The first category, 'Welcome to Dementia', captures the traumatic aspects of the experience of receiving a diagnosis, which is influenced by societal expectations and stigma associated with dementia ('Perception vs. Reality) and the 'Loss' typically associated with receiving a diagnosis. The next category captures the initial response to receiving a diagnosis, which broadly falls into three themes: 'Depression'; 'Anger'; and 'Relief'. It explores how participants typically fell into feelings of 'Depression' or 'Anger', but also acknowledges how many appeared to oscillate between one of these negative states and 'Relief', which intensified confusion.

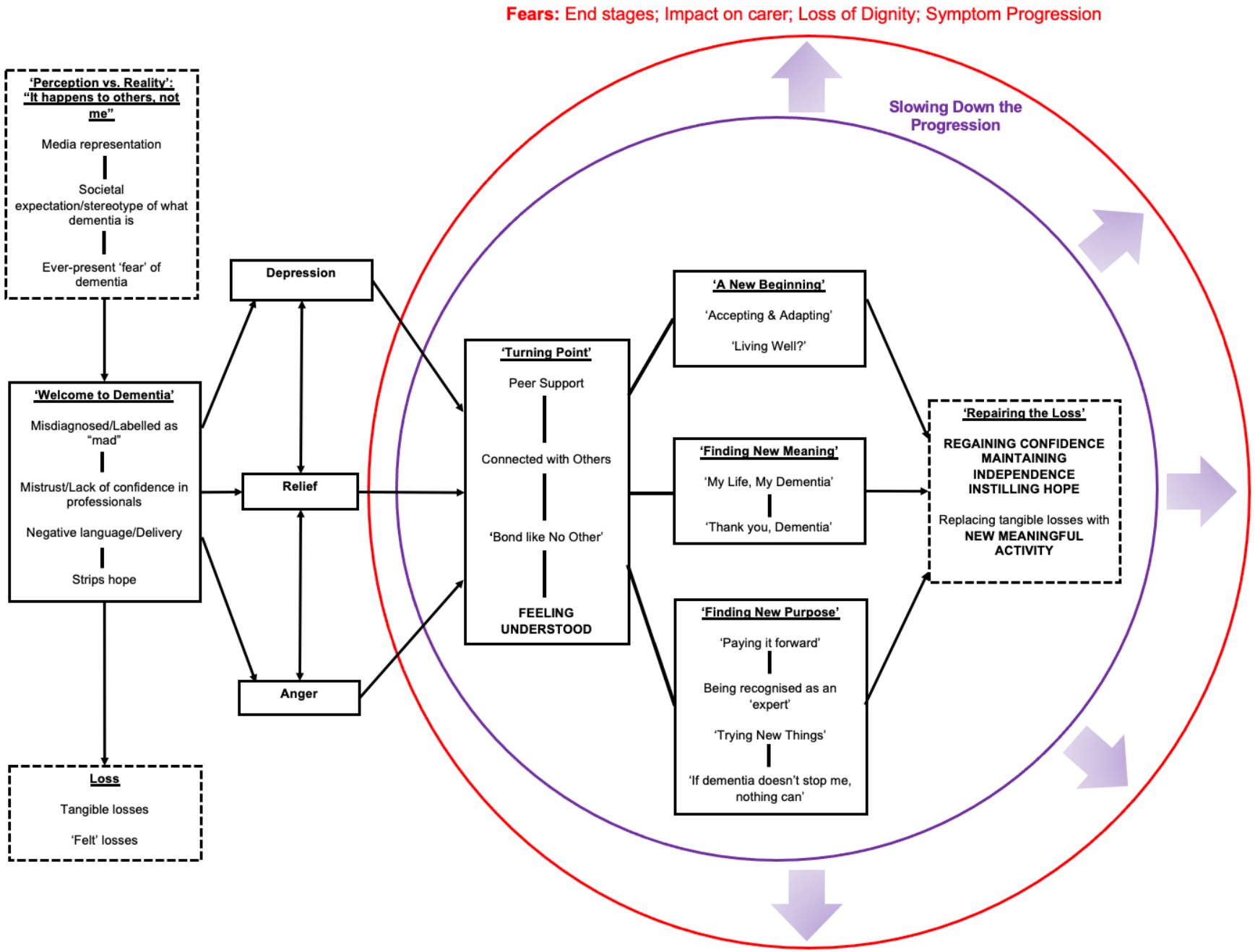
The third category acknowledges the 'Turning Point'; the point at which participants' mindset began to change and they appeared to shift into a position of 'growth'. Participants attributed this shift to their engagement with 'peer support' and the shared understanding this created with other people living with dementia.

This 'Turning Point' and the new connections they had made, appeared to reveal new opportunities for participants, which were conceptualised within three broad categories: 'A New Beginning'; 'Finding New Meaning'; and 'Finding New Purpose'. 'A New Beginning' captures participants thoughts on how receiving a diagnosis of dementia meant they began to live a different life to the one they had originally planned. Within this category, participants' experiences of 'Accepting and Adapting' to living with dementia and their thoughts on 'Living Well?' are captured.

‘Finding New Meaning’ discusses the new narrative participants have created for themselves and their lives and explores how participants are living with, and ‘owning’, dementia in their own way. ‘Finding New Purpose’ captures the meaningful activities participants have become engaged in since receiving a diagnosis and the positive impact this has had on themselves and others. It is acknowledged that these categories and the themes included within them represent a process of reparation (‘Repairing the Loss’) that enables growth to be experienced.

Finally, the two circles encapsulating the process from the ‘Turning Point’ onwards represent the ‘Impact of PTG’ and the over-arching processes that occur alongside the experience of PTG. The inner circle represents a belief that the categories included within it have slowed down the progression of the disease. The outer circle represents the over-arching fears that are still understandably present for those living with dementia. The arrows between the two circles capture participants beliefs that ‘Slowing Down the Progression’ goes someway to counteracting or ‘pushing back’ these fears.

Figure 2: *Grounded Theory Diagrammatic Model*



‘Welcome to dementia’

‘Welcome to dementia’ describes participants’ experiences of the diagnosis process and is influenced by the themes of ‘Perception vs. Reality’ and ‘Loss’.

All participants spoke of their own diagnosis being the first time they had personally been confronted with dementia and described it as a long and negative process. Many reported feeling ‘kept in the dark’ about professionals’ suspicions and having been misdiagnosed with other conditions prior to receiving their dementia diagnosis. Participant 3 spoke about the lengthy journey to diagnosis: *“…for 16 months I was kind of scanned and prodded and poked and tested […] and eventually after about 16 months, 18 months, I was diagnosed with young-onset Alzheimer’s disease […] it was a long-drawn-out affair”*.

This experience was echoed by participant 1 who described being passed between professionals during their diagnosis:

> *“[…] and then, ‘you need to go and see errr, a Psychologist’. So, I went to see a Psychologist, and then I was seeing this Psychologist for about 6 months. Then I […] started getting worse […] So then, said ‘you need to err go and see a Psychiatrist’, so I went to see a Psychiatrist…for about six months […]”*

A common theme was the misdiagnosis of dementia symptoms as a mental health condition even when this did not fit with the person’s understanding of the experiences they were having:

> *“I was diagnosed with depression for four years. Which I did feel a bit odd about because even though I've had a traumatic sort of - from the age of 17 until I was 40 was quite a traumatic time. […] I've always stayed positive, so the fact that I was diagnosed with depression was a bit strange.”* (participant 5)

The consequences of this could be dramatic, including hospitalisation:

> *"[…] he phoned me and said, 'I have managed to find you a bed but it's quite a way away, and if you don't mind being a walk-in patient on a psychiatric unit'. […] I was so desperate for some kind of help, that I said, 'yeah, I'll go', and so I was admitted there and I ended up staying for a month […]"* (participant 9)

These accounts suggest communication between professionals and those accessing services for dementia diagnosis can be poor, and participants can feel not listened to during their journey to diagnosis: *"I just wish […] more professionals would listen"* (participant 4). People also described being 'kept in the dark' by professionals and not being informed of their suspicions:

> *"But nobody mentioned the word dementia until I saw it in the first letter that I received. Well, my Dr received it and she always sends me a copy. And it was then it said, 'suspected or possible dementia'. And that was the first time anyone had mentioned that to me. Y'know that's not a very nice way to find out."* (participant 8)

It is therefore perhaps unsurprising that participants spoke of now having a lack of trust in professionals and clinical services:

> *"Frustrating in a sense that if professionals had the nous, they could use our knowledge to help […] But the problem is most professionals think they know best because they've done all the work and have got titles up their name and all that rubbish.* […] *and most of them don't listen"* (participant 4).

For some, this results in a hesitance to access services: *"And I say now that I would be very reluctant to get any…to go and ask for support now anyway. Because I*

wouldn't be convinced that I'd get someone that knows what they're doing" (participant 8).

Furthermore, participants described the negative terminology used during their diagnosis and the impact this had on their ability to live with dementia. The diagnosis could be delivered as 'bad news', often with the 'good news' being presented as them not having the condition they were originally diagnosed with: *"I've some good news for you, and I've some bad news for you […] And he said, 'the good news is you haven't got Bipolar' […] so he said, 'well the bad news is, you've got Young-Onset Dementia, Alzheimer's'"* (participant 1), or being presented as 'passing' the assessments: *"He says 'ah Mr [Name]', he say 'you've passed'"* (participant 3); or 'failing': *"Anyway, I failed"* (participant 5).

This led to people feeling hope had been stripped:

> *"It was the effect it had on me that was more negative. […] The psychological effect of words and body language should never be underestimated by Healthcare Professionals, because we think you know best […] So, if only they turned that around and said, 'yes it's a bummer of a diagnosis and there's nothing I can do, but there's still much life you can still live', then at least that would've given me some hope. Hope is the one thing we never get at diagnosis."* (participant 8).

'Perception vs. Reality': "It happens to others, not me"

Participants spoke of the stigma and stereotypes of dementia which exist within society and how this influenced their perceptions of what living with dementia would 'look' like. Participant 1 spoke of not being aware of the stigma until after he had

received the diagnosis and how this influenced his thought process immediately following diagnosis:

> *"…what I didn't realise as well was, was the stigma that comes with it […] I thought…'oh my god, my life's gonna be over now […] 'this is what the end of your life feels like' […] 'but how come I can still think y'know if I've got Alzheimer's? How come I'm able to…think and talk and function'".*

Participants highlighted how the stereotypical view of dementia is of the end stages: *"Everyone has this perception of what Alzheimer's and dementia is, like. And first thought is the end thought. [...] And I can understand. That was my first thought whenever I, er, heard about dementia. Because that's all I saw…"* (participant 3);
and how this view appears to be perpetuated by the media:

> *"[…] if someone had said to me…they're gonna tell me I've got…Alzheimer's…I would've not been able to remember anything or […] do anything, because that's exactly how I thought people with Alzheimer's […] were like…y'know…as they're portrayed in the media […] as, in the latter stages of it […]"* (participant1).

As a result of these stereotypes, participant 2 spoke of previously feeling like dementia was something that happened to 'other people': *"you don't know anything about dementia. It's what other people have got, not yourself…it's one of those, y'know. Other people get these things, not me"*. Similarly, participant 5 spoke of her belief that she was too young to have dementia: "[…] *dementia never entered my head. Because I just thought, although I'm not young at 59, I thought it was for people in their 80s*". Both participants later quashed these narratives by highlighting the

differences between the preconceived expectations they had about dementia and their current reality.

'Loss'

Participant's spoke openly about their losses, including tangible losses such as jobs, cars, houses and friends, and more existential losses such as confidence, freedom, identity, worth and hope. When discussing tangible losses, participant 1 said: "*[…] I lost everything […] I lost my job… and then they took away my driving license…and then…because I had no job, err we had to downsize our house".*

For some this could result in them losing their sense of identity: *"[…] they didn't think that person was still there, like y'know […] [I was] now a disease rather than a person"* (participant 1), and worth: *"And you do feel quite worthless actually. You can't contribute to society in any sort of way, like."* (participant 3).

'Initial Response to Diagnosis'

Participants spoke of initially responding to their diagnosis in one of two ways: **'depression'** or **'anger'**, Some participants reported oscillating between one of these emotions and **'relief'**. **'Relief'** often grew from having an explanation for their symptoms or from not having the condition they were originally misdiagnosed with.

'Depression'

Many participants spoke of becoming depressed initially following their diagnoses: *"I got a bit - I really got a bit depressed at that stage"* (participant 4); and: "*Yeah, it was very bleak. […] I went into a real, quite bad depression then"* (participant

5). Participant 3 described being so 'devastated' he contemplated suicide in the early stages:

> *"[…] it had a huge devastating effect and I have to be honest probably for the first three or four weeks, erm, I sat in the house doing nothing. […] I thought there was absolutely no point, er, whatsoever. And, I was actually really close to, er, doing something silly, like. To be honest."*

Participant 8 attributed her depression to the diagnostic process: "*…when we get a diagnosis […] yes, we sink into depression because of the clinical process."*.

Participant 1 spoke of the loneliness and isolation experienced once diagnosed, which intensified his depression:

> *"and that's when I found out that being in a room full of people is the loneliest place on earth. When you're ignored…because, […] when you're in a room full of people and they ignore you, and talk about you as if you're not there…that's the loneliest place on earth, y'know, it really is, a lonely place"*

'Anger'

Other participant's spoke of responding angrily to the diagnosis. Participant 2 spoke of his initial response to the Psychiatrist who gave him the diagnosis:

> *"…I said to him, 'I haven't got it, you're wrong, you're totally wrong'. […] And we had a little, y'know…I wasn't nasty or anything, but I was made up when he was gone".*

Participant 2 also reflected on his use of avoidance, denial, and alcohol as coping mechanisms:

"I was rejecting everything at the time. I was in denial, so I never […] bothered, I never even answered the phone from [care team] […] I was drinking heavily as well at the time. I didn't tell anyone neither."

'Relief'

Occasionally participants would oscillate between these two negative emotions and in and out of 'relief', which stemmed from not having the condition they were initially misdiagnosed with.

"It was...a mixture of relief, believe it or not […] Er, because - because it wasn't motor neurones." (participant 3)

Participant 7 spoke of the relief that came with having an explanation for his symptoms: *"[…] It was absolute relief, absolute relief, yeah. The certainty of the - of the diagnosis. […] I think getting confirmation of something that I knew."*

'Turning Point'

Participants spoke of the importance of **peer support** following their diagnosis and how this became the 'turning point' for growth: *"It changed my life, it really did […] It should be given out on prescription – peer support. Because, y'know, I'm happier now"* (participant 5).

Participants accessed peer support in a number of ways, either through groups such as post-diagnostic support or through making individual connections. Peer support enabled participants to feel more connected to others due to them having a '**shared understanding**' of what each other was going through:

"I think that's been such an amazing experience […] just sitting with people who know exactly what you're going through and even if you have a bad day, they

don't judge you, and just let you get on with things […] they laugh with you, they cry with you. And it's, err, quite an amazing experience" (participant 3).

This experience was echoed by participant 8 who spoke of the 'empowering' nature of peer support:

"[…] the biggest support I get is from other people with dementia. […] there's nothing more empowering than hearing someone say, 'Oh, I do that too', you're not alone anymore. You're sharing ideas, you're sharing the bad days, you're sharing the laughter".

This unique position of being able to relate to each other and share the 'highs and lows' created a '**bond like no other**' between people living with dementia: *"There's a real special bond there like, that I've never properly had before"* (participant 3).

'A New Beginning'

'A New Beginning' captured participants' experiences of adjusting to living with dementia and their thoughts on the idea of 'living well' with dementia.

'Accepting & Adapting'

Participants spoke of having learned to accept and adapt to their diagnosis: *"I think it's just that I've adapted well […] Now you just think it is what it is, it happens. We'll just have to and find a way around it […] Learn to adapt with your life"* (participant 3).

Others spoke of the importance of having support in being able to build a new life: *"me world's different now, but it's grown out a little. So with the right help and support…y'know, you're able to recreate and rebuild your life…different life…but at least it's not confined"* (participant 1). Participant 2 said: *"[…] when you come to terms*

with it, then you can expand your thoughts a little bit then and try and get back into the groove of living". Participant 3 spoke of being on a new journey: *"It's actually just a new journey. And it's a great journey"*.

'Living Well?'

Many participants spoke of their life being better in some ways than it was before: *"It's a completely different life, like. From what it was before, life. Actually, in some ways, it is a better life"* (participant 3), which was echoed by participant 1: *"[…] turns out, it wasn't the end of my life, it was the beginning of my life"*.

When asked about the terminology and how they felt about the term 'living well' with dementia, some felt it captured their experiences well: *"I think it's a great term. I think it explains it absolutely perfectly. You can. You can live well with dementia"*. Others on the other hand, felt that the term was giving out the wrong message and that it suggests people have a choice of how they live with their diagnosis: *"[…] it's just used for everyone and I…it's giving out the wrong message I think really […] it makes it sound as if you've got a choice doesn't it?"*. Participant 2 described feeling 'hurt' by the term: *"it hurts me…that's how I feel about it […] nobody lives well with it."*.

Participant 5 acknowledged that 'living as well as you can' may be a more fitting term: *"I don't like it, because nobody lives well, do they? I don't think. I like to say, 'I live as well as I can with dementia'"*. Participant 8 agreed and expanded, stating 'living well' places high expectations on people living with dementia:

> *"[…] I have a problem with that term […] since meeting so many other people, I realise it puts such a high expectation on people that some can't reach, or they feel they can't reach it. […] So now I simply use, 'living as well as your*

circumstances will allow' […] and then no matter what's people's personal or financial situation, they can achieve something, albeit tiny […]".

'Finding New Meaning'

This category explores the ways in which people living with dementia create a new narrative for themselves, their lives, and their dementia, post-diagnosis.

My Life, My Dementia

Participants spoke of the importance of living their own dementia, their own way: *"And it's up to me, y'know. It's my life. It's my dementia. […] My condition has to fit in with the way I need my life, not I've got to fit with the Alzheimer's […]"* (participant 5).

Other participants described a change in outlook once they received their diagnosis: *"I don't take on negativity now […] I just live for the moment"* (participant 5). Participant 4 spoke of how negative things that happened in the past no longer feel relevant: *"I used to obsessively ponder say on the tribulations […] of my childhood and that but I've just – they're locked away in a drawer now. They're irrelevant"* (participant 4). Other's spoke of regaining a sense of agency and re-aligning their personal goals:

"I'm a stoic. I am where I am, there's no point ranting about it. […] It is what it is. Get all the difficult bits out of the way, but then just sit back and extract every little bit of goodness out of the time you've got left that you can" (participant 7).

Participant 8 saw it as a 'sink or swim' opportunity: *"And then we either…carry on sinking or we develop and realise there's a life"*.

Others recognised that while they had created a new narrative for their lives, their old narratives were still just as important:

> *"I always say, we all had talents before a diagnosis of dementia. We don't suddenly lose those talents overnight when we get a diagnosis. We were a mum before dementia, we are a mum after dementia."* (participant 8);

And: *"You're still you, I mean they say, 'oh, you lose that person in the later stages', but you don't because there's that golden thread of that person that's still running through there"* (participant 5).

'Thank you, Dementia"

Some participants spoke of being grateful to dementia for the things it has given them and the experiences it has afforded them. Participant 7 spoke of being more creative since his diagnosis and being able to write blogs, poems and rap songs, which he could never do before: *"I'm thankful for it. […] I couldn't do that before, and I could do that now. Alzheimer's has done that for me, y'know. So, thank you Alzheimer's".*

Others spoke of dementia giving them *"wings"* (participant 5) and acknowledged the travelling and media opportunities that have been offered to them:

> *"[…] dementia's giving me so many opportunities. I always call it a sideswipe at dementia […] all the travelling I've done, and all the people I've met in different circumstances. Being on the tele, being on the radio, y'know, nothing like that would've happened […]"* (participant 8).

Participant 8 went on to speak of dementia giving her the space and time to enjoy life:

> *"It's slowed me right down has the dementia, but in a good way, because it's allowed me to enjoy the day and life, instead of…y'know, we spend our lives*

[…] wishing our lives away. When, in fact, dementia allows you time…to enjoy today".

'Finding New Purpose'

This category relates to participant's finding new and meaningful activities which have enabled them to remain motivated and provided them with a sense of achievement and has enabled them to recreate their identity in light of dementia.

'Paying It Forward'

'Paying it forward' recognises many people living with dementia have gone on to support others living with dementia by setting up peer support groups, engaging in public speaking and sharing their experiences widely. Participant 1 spoke of sharing his experiences far and wide and how it has inspired hope in others:

"…they said, 'would you do a little talk about what it's like living with dementia?' […] so I did that and then they said, 'do you want to come every week?' […] a few years later y'know, [the OT] and [the Psychologist] asked if I'd go to Holland with them and talk over there so we did that […] Most important is the post-diagnostic group because […] one of the fellas, he pointed at me and said, […] 'you've given me hope'. And that's all we wanna do".

Some perceived this as *"inspiring the next generation of people living with dementia"* (participant 1), recognising the impact this may have on future generations:

"I look at it as a legacy for people in the future. There's not much I can about me now, but hopefully people can change so it's more understanding in the future like" (participant 3).

Participant 5 eloquently spoke of how important it was for her to feel like she is making a difference to the experiences of others living with dementia:

> *"I've had lovely feedback from people. […] I got this letter from a lady. I kept it because it's just so special to me. Who'd said she'd heard me speak […] - and her mother had dementia […] and they were arguing all the time […] And she said after she went home from that talk […] she saw her mum in a different light. […] That's why I'm doing it. Because I make a difference to people."*

Participant 7 also spoke eloquently about his experiences of sharing his story:

> *"Yeah I do a lot of public speaking. […] It's a bit like, er, exhibiting a monkey I suppose. I can tell them a little bit about my life, they'll understand me a bit better, they'll understand dementia a bit better. And then they'll want to ask me a few questions. […] They'll tell me how brave I am, as if I'm brave because I didn't have a choice. I've got dementia. It chose me, I didn't choose it."*

Many participants described their actions as 'selfish': *"[…] people say 'oh you're brave to tell your story'. I'm not. I'd say I'm probably quite […] Selfish of me, I think like. Selfish because it helps me."* (participant 3), and: *"I'm doing it for selfish reasons. I never pretend I'm doing it altruistically"* (participant 4). Others spoke of *"get[ting] a high"* (participant 4) and *"feel[ing] a sense of achievement"* (participant 7) by helping others.

There was a sense that by 'paying it forward' and helping others by sharing their stories, participants were **being recognised as 'experts'** in their own right. Participant 8 acknowledged her own expertise and how this differs from the expertise of clinicians: *"[…] you're the clinical experts at diagnosis, but we're the experts by experiences. We're living it […] In the world of dementia we have a saying, 'nothing about us, without us'".* Participant 2 echoed a similar theme: *"I'm not particularly kind*

to academics I don't think…because that's the thing, they're not the experts, I'm the expert". Participant 8 highlighted the importance of experts-by-experience involvement in all levels of discussion regarding dementia: *"Because if you're talking anywhere – whether it's the health service or parliament or politics y'know – if you're talking about dementia, you should have people living with dementia present"*.

'Trying New Things'

Participants spoke of the importance of having a focus: *"if you have something to look forward to, something to get out of bed [for], you've got a bit of a focus y'know"* (participant 2). Many participants find their focus in trying new hobbies they had never thought of doing before: *"I'm discovering all these things that I can do now. This writing this blog all of these things that have come out since my diagnosis.".* Participant 3 also shared this experience of learning something new:

> *"[…] I've done so many things since being diagnosed that I would never have dreamt of doing before […] Never touched [poetry] in my life. Never touched it in my life […] You try new things that you would've never thought of doing before […]."*

Many spoke of being shocked and surprised at what they were able to achieve. In relation to his poetry, participant 3 shared: *"[…] I was quite surprised, quite shocked and surprised at what comes out of my head sometimes, like"*. Participant 5 shared her account of doing new things, which included being able to take positive risks and how dementia encourages her to do what she wants, as opposed to preventing her:

> *"I mean I went down to do a talk in [place]. And, erm, somebody asked me would I go white water rafting for charity. And I did. […] God, I loved that white*

water rafting. And if I'd had got tossed in a drowned, well I was happy. […] And it's my choice. I'll take those positive risks.

'Impact of PTG'

Participants described the impact of PTG as having repaired some of the losses they felt when initially diagnosed. This category also captures participants' belief that PTG has slowed down the progression of their dementia.

'Repairing the Loss'

Participant 1 reflected on how it felt attending meetings with professionals and being asked to contribute: *"every time I went then I was asked my opinion, so I started to get a bit of confidence back"*. Whereas participant 3 reflected on the confidence gained by starting his own peer support group: *"It's been amazing. […] it has built my confidence back up again. Because after the diagnosis you do lose a lot of your confidence*". While participant 5 reflected on gaining confidence she never knew she had: *"[…] I've learnt to speak up for myself now. I've got my confidence, they've [third sector organisation] given me my confidence […] I'd put myself down, and they would say to me y'know, 'every voice is important…"*.

Participant 3 also reflected on regaining his sense of worth:

"[…] [sharing my story] makes me feel worthwhile. […] the amount of loss after diagnosis is huge. And you do feel quite worthless actually. You can't contribute to society in any sort of way".

Additionally, participants highlighted how important independence was to them:

"I like to be independent. I like to do as much as I can while I still can" (participant 3), and how it made them feel less of a burden: *"I don't want to interfere with [their] life"* (participant 6). Others spoke of having been able to maintain their independence for longer than they expected, having initially experienced others 'doing to' and 'doing for' them rather than 'doing with' them: *"…they were doing things to me as opposed to allowing me to be"* (participant 8).

'Slowing Down the Progression'

This category highlights the belief held by participants that by engaging with peer support, finding new meaning and purpose and acknowledging that dementia can be a new beginning for them, it has enabled them to keep busy, 'keep their brains active' and as a result, they believe their dementia progression has been slowed down. This belief about slowing down the progression of their dementia creates a tension between the above themes and the '**Fears'** noted below.

Participant 1 spoke of feeling like dementia would have 'taken him' had he not engaged with the activities he does:

> *"I work along with my other friend […] we do group work y'know […] we were saying that if we hadn't have had any of this to do, […] the dementia would have took us".*

Participant 7 acknowledged that the preparation he does for public speaking enables him to advance certain parts of his brain where other parts may be failing:

> *"[…] That keeps me sharp as a razor. And I'm convinced that that is holding my dementia at bay to a certain extent. […] The fact that although I've got holes in my brain now where information is falling through – my brain is performing in other respects better than it did before"*

When asked what engaging in this meaningful activity does for her, participant 5 acknowledged that if she was not keeping her brain active, she would have become the burden she always feared she would become: *"Well, I think I'd be further along […] because I wouldn't be activating my brain […] and would've felt a burden, I think. And would've become a burden".*

'Fears'

Despite many of the participants talking about the positives of living with dementia, many acknowledged the understandable fears they have, which can shadow their experience. For many, these fears relate to symptom progression and the end stages of dementia, and how this may impact on their dignity and their loved ones.

Participant 3 spoke of his fear, whilst also acknowledging it is something he has limited control of: *"I certainly know what's coming and it kind of scares me a little bit. But, what can you do? It is what it is".* Participant 7 spoke of his worry of how the future may impact his wife:

> *"[…] I have no worries about my own future because I know pretty much what that's going to be, I just don't know the length of it. My only worry is the nuisance and burden I might be to [wife] later on. And that's always on my mind. […] that's purely where my pain lies."*

This highlighted the impact that is felt by both the person living with dementia and the carer.

Discussion

This research is the first to the researcher's knowledge to explore the concept of PTG in people living with dementia. Participants described how their dementia diagnosis had been perceived as the trauma on which their new life trajectory was founded. This research extends the current growing body of literature examining 'positive psychology' concepts in relation to dementia (Wolverson et al., 2016) and indicates the factors involved in the experience of PTG in dementia.

The proposed model suggests that PTG in dementia is not a standalone, one-off event, but rather an experience which develops and heightens over time. It also suggests that PTG can continue to develop, despite the ongoing trauma of living with dementia. This supports Tedeschi et al. (2018)'s contention that PTG should be regarded as both a process and an outcome, suggesting PTG and the trauma of being diagnosed and living with dementia, can be parallel experiences as opposed to being regarded as separate disparate processes. This notion is also consistent with Aspinwall and Tedeschi (2010) who acknowledged that positive and negative experiences can co-exist in a way which may assist in the processing of negative experiences. It also provides an alternative to the 'living well' narrative and acknowledges a balance can be struck between the 'trauma' of dementia and 'living well'.

Within the first category, 'Welcome to dementia', participants' narratives highlighted the traumatic nature of receiving a diagnosis of dementia, which is consistent with previous research (Aminzadeh et al., 2007; Steeman et al., 2006). It also captures the impact of the actual and expected losses for people living with dementia, as supported by previous literature (Hydén et al., 2014; Mitchell, Sherry, et al., 2013). Many participants spoke of initially being misdiagnosed, often with mental

health conditions, prior to receiving their dementia diagnosis; and this, combined with the way their dementia diagnosis was delivered, has resulted in a lack of confidence in professionals and clinical services. This category and the themes within it align well with Calhoun and Tedeschi's assertion that *"it is not the event itself that defines trauma, but its effect on schemas, exposing them to reconstruction"* (Calhoun & Tedeschi, 2004, p. 100). Therefore, it is not the dementia itself which is regarded as the trauma; but rather the impact of the diagnostic process and loss associated with it, that results in the individual's preformed beliefs about themselves, others and the world being challenged; and the process of these beliefs being reconstructed in a way which enables them to form a new life path for themselves.

The findings identified the role of societal stigma in relation to dementia and how this impacts people living with dementia, especially in terms of their initial reaction to the diagnosis. Previous research has shown stigma and discrimination of dementia to be prevalent both in the UK (Benbow & Reynolds, 2000; Milne, 2010) and elsewhere (Riley et al., 2014; Swaffer, 2014; Woo & Chung, 2013). Milne (2010) acknowledged a combination of stigmatising experiences for people living with dementia: 1) the negative responses from others; 2) the internalised stigma resulting from their own preconceived beliefs; and 3) age-discrimination, resulting from dementia often being associated with later life. Additionally, the Department of Health (2009) openly acknowledged the stigma and discrimination faced by people living with dementia and how improving the public's understanding of dementia is key to addressing these negative stereotypical beliefs.

Participants identified their initial reactions to the diagnosis as either depression or anger, whilst some acknowledged also feeling a sense of relief. This is consistent with Aminzadeh et al. (2007) who found on receiving a dementia diagnosis, people

responded in one of three main ways: appearing to lack insight and/or actively denying the diagnosis; grief reaction or emotional crisis due to anticipated or actual loss, or; positive coping to minimise disease impact. It could be argued that these three categories broadly align with the three mediating factors (anger, depression, relief) identified within the current research. However, it is important to acknowledge Aminzadeh et al. (2007)'s study was completed with a limited sample recruited from one Day Hospital in Canada, and it is therefore possible that the results cannot be generalised to other populations, especially populations which may access NHS services.

The importance of peer support in participants' experiences of growth following dementia diagnosis was captured within the 'Turning Point' category. Participants spoke of peer support enabling them to connect with others who they felt had a shared understanding and experience. Peer support was also used as a mechanism for sharing ideas and coping strategies. Previous research has highlighted the importance of peer support for people living with dementia (Keyes et al., 2016; Willis et al., 2018). Keyes et al. (2016) conducted qualitative interviews with 101 people living with dementia and 82 staff, with the aim of evaluating the impact of 40 sites where peer support was either facilitated or actively encouraged via signposting. Peer support was found to have emotional and social benefits for people living with dementia due to its reciprocal nature and it offering them an opportunity to identify with others with whom they had a shared understanding. These findings are consistent with the current research. However, previous research has also highlighted peer support may not always be positive (Greenwood et al., 2013) and therefore Keyes et al., argued the importance of ensuring that peer support is not seen as a replacement to clinical services.

It could be argued the ‘Turning Point’ category is similar to the ‘relating to others’ domain originally identified by Tedeschi and Calhoun (1996). These constructs both capture the experience of positive change in the way people connect with and relate to others. Tedeschi and Calhoun suggest this may involve a change in not only the relationships themselves, but also in the attitudes and beliefs attached to relationships. This was also seen in the current research, with participants expressing a loss of some relationships that no longer felt productive for them and a change in the way they viewed their new relationships.

Following engagement in ‘peer support’, participants were offered new opportunities which were captured by three categories. ‘A New Beginning’ acknowledges participant’s being able to accept and adapt to their dementia and ensure they are still able to live a positive life, despite the limitations of the condition. Bjørkløf et al. (2019) conducted a systematic meta-synthesis of 74 research articles with the aim of identifying how people living with dementia cope with the challenges of the condition. Humour and practical and emotional support were found to be the two main coping resources, with ‘keeping going’, ‘adapting and adjusting’, ‘accepting’ and ‘avoiding’, being found as the four key coping strategies. These coping strategies are consistent with the themes emerging within the ‘A New Beginning’ category, which could also be compared with the ‘appreciation of life’ and ‘new possibilities’ domains identified by Tedeschi and Calhoun (1996).

The original ‘appreciation of life’ domain described people seeing life as a second chance which should be cherished and having a greater appreciation of the things they may have previously taken for granted (Tedeschi & Calhoun, 1996). Participants within the current research identified feeling as though dementia was the start of a new life for them; a life which can, in many ways, be better than the life they

lived before dementia. Additionally, the 'new possibilities' domain describes the experience of individuals taking a new and different path in life (Tedeschi & Calhoun, 1996), which also appears to capture elements of the current participants experiences.

'A New Beginning' also captures the wide array of opinions relating to the term 'living well with dementia'. This term has been subject to debate for a number of years, but criticism recently grew following comments made by Professor June Andrews, an eminent dementia specialist (Naysmith, 1999). Professor Andrews stated it was wrong to think you can 'live well' with dementia and actually the reality is *"really grim"* (Naysmith, 1999). Her comments sparked a media and social media debate, with many criticising those who claim to 'live well' as lacking in insight. During these debates, one of the key criticisms voiced about the term 'living well' was that it failed to acknowledge the negative side of dementia and therefore made those who felt unable to 'live well' like they were somehow failing. These views were supported by the current research, and it is possible that the term PTG acknowledges the difficulties of living with dementia whilst simultaneously recognising that some will go on to live a different but more fulfilling life.

Tedeschi and Calhoun (1996)'s 'new possibilities' domain also captured the notion of people developing new interests, activities, and hobbies, which they would not have considered engaging in prior to the trauma. This domain mirrors the participant's narratives captured by the 'Finding New Purpose' category. This category describes how participants became recognised as 'experts' by sharing their stories with other's living with dementia, professionals and lay people. Furthermore, it expresses the participant's motivations to engage in new activities which enabled them to gain a sense of achievement. Research has previously highlighted the benefits for people living with dementia when involved in fundraising (Bartlett, 2014; McConnell

et al., 2020), consultation (McConnell et al., 2020), raising awareness (Schicktanz et al., 2018), public-speaking (Bartlett, 2014), and in activity more generally (Phinney et al., 2007).

'Finding New Purpose', therefore also closely relates to the 'personal strength' domain described by Tedeschi and Calhoun (1996). 'Personal strength' was defined as an increase in strength and confidence and a clear sense of self. It can involve people gaining a sense of there being nothing that they cannot achieve, which can lead to behavioural change and individuals engaging in completely new activities (Shakespeare-Finch & Barrington, 2012); a notion which challenges some of the more traditionally held views of dementia which assert that people living with dementia cannot learn new skills.

Participant's spoke of 'Finding New Meaning' which involved them creating a new narrative for themselves and their lives. Within this category, participants spoke of the opportunity's dementia had afforded them and the importance of living their dementia their own way. As a result, this category can also be compared to the 'appreciation of life' domain described above (Tedeschi & Calhoun, 1996).

The final category acknowledges the impact of PTG. Participants spoke of the above categories repairing many of the losses they experienced when they were first diagnosed. It was believed that by accessing peer support and the opportunities this brought about, it led people living with dementia to feel understood, regain their confidence and worth, and maintain independence; while engaging in new meaningful activity allowed them to establish a new routine and fill their time with new activities. Participants believed these experiences were helping to slow down the progression of their dementia, which was allowing some of their fears, particularly around the later stages of dementia and their symptom progression, to be kept at bay. This is an

outcome which, to the author's best knowledge, is currently under-researched, however this is likely to be due to the difficulties in measuring and evaluating whether the progression of dementia is slower than it would typically be.

Clinical Implications

The theoretical model highlights the negative narrative which is still perpetuated during the process of obtaining a diagnosis of dementia. It is important for services and professionals to work hard to shift this narrative and acknowledge that growth following dementia diagnosis is possible. Moreover, it is important for services to be mindful about the way in which a diagnosis is given and the language they use, striking a balance between giving a realistic account of the difficulties whilst not stripping the individual of the hope of living a good life as it is clear this has a significant impact on their ability to experience growth. However, previous research has highlighted the difficulties psychiatrists face in delivering a diagnosis in this way (Vince et al., 2017). One way in which we can support this narrative in being changed, is to increase dementia education for pre-qualified professionals, especially education which actively involves and is led by people living with dementia as 'experts-by-experience'.

This research has shown the importance of 'peer support' following diagnosis and there is a need for clinical services to promote and support such engagement. One way of doing this would be for services to include people living with dementia in post-diagnostic support, and by services becoming more aware of Third Sector organisations which 'plug the gap' that clinical services cannot fill.

Although not directly quoted here, many participants referred to the 'postcode lottery of support' in relation to dementia services. If the figures quoted earlier are accurate and it is expected that over 1 million people will be living with dementia within

the next five years, then it is crucial for services to receive additional financial support to adequately meet this growing demand. A national dementia pathway through NHS and Social Care services, which would offer a streamlined diagnosis and follow-up process, with adequate post-diagnosis support and stronger links between these and Third Sector services, would be one way of meeting such demand.

Strengths and Limitations

As is typically the case within Grounded Theory research, the aim was to recruit a heterogeneous sample which would reflect a wide variety of views; however, there were a number of barriers to doing this, and as a result, the sample is biased towards white males with young-onset Alzheimer's disease in particular. It is possible that people living with dementia from diverse backgrounds, females, and those living with the rarer dementias may have a different perception of PTG in dementia. This is an area which would benefit from further exploration. Additionally, the sample size is small, and it is important to acknowledge that the model developed is based on the experiences of only nine participants who were all actively engaged in public-facing activities. Therefore, the experiences of those who are not involved in raising awareness, campaigning, peer support, and other expert-by-experience roles, may differ.

There were, however, some strengths to the employed sample. Firstly, participants varied in the lengths of time in which they had been living with their diagnosis. The range of disease duration was between 2 and 16 years, suggesting that PTG may not be influenced by disease duration. Additionally, individuals from a wide range of backgrounds and with a variety of life experiences were also recruited. Some participants recalled being driven with a positive life outlook prior to diagnosis, whereas others reported a number of difficult life experiences which had impacted

negatively on their view of self and the world. Regardless of prior experiences and outlook, it should be noted that all participants reported some degree of PTG, therefore suggesting that pre-morbid life satisfaction may not influence experience of PTG.

A further limitation to the research was the level of expert-by-experience involvement. Initially, it was planned for people living with dementia to be involved during every stage of the research, however the COVID-19 pandemic became a barrier to this. Experts-by-experience were therefore consulted on the original research idea, which involved a different methodology and analysis, however amendments needed to be submitted quickly and there was no opportunity to gain further opinion before this was done. They were, however, involved in the initial designing of the research question, approving the original study documentation, recruitment, and will be consulted with regards to further dissemination.

Finally, it is important to acknowledge that the quotes presented here represent a snapshot of the participants views and there appears to be more quotes included from some participants compared to others. Throughout the interviews it became apparent that some participants were more experienced in sharing their story and therefore presented themselves and their experiences more eloquently than others. It is therefore important to acknowledge that all quotes gained from all participants were included in the coding and therefore are captured by the categories and themes documented in the model, despite many of the quotes not being included in the results.

Future Research

This research highlighted that people living with dementia feel a forced sense of agency in creating peer services which ‘plug the gap’ clinical services cannot meet. It was clear this factor provided a ‘springboard’ for PTG, and it is important to determine whether growth would still occur if clinical services were to begin to ‘plug

this gap' or whether there is something about this sense of agency which acts as a motivating factor for growth.

Further research is also required around the mediating factors identified, which are the emotions felt immediately post-diagnosis. In this research, these were identified specifically as 'depression', 'anger' and 'relief'. The exact role of these factors needs to be investigated further, and what motivates some to progress towards the 'turning point' while others do not. Finally, the proposed model would benefit from further testing to ensure validity. One way of doing this may be using longitudinal methods to 'map' the course of PTG in dementia and determine whether people's experiences are represented by the model.

Conclusions

In conclusion, the current research utilised Grounded Theory to explore the experiences of PTG in people living with dementia. The findings highlight the traumatic nature of receiving a diagnosis of dementia, and how it often leaves people feeling stripped of hope, confidence and worth. It has also been highlighted that PTG is an ongoing process which appears alongside the ever-present fears people living with dementia have for their futures. The importance of peer support has been recognised, and how this, along with people living with dementia being able to construct a new narrative for themselves and their lives which involves meaningful activity, has enabled them to repair some of the losses they initially felt when diagnosed. Finally, it has been highlighted that people living with dementia have the potential to not just 'bounce back' from their diagnosis, but to grow as a result of it and create a life that may in many ways be better than the life they lived prior to dementia.

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APPENDICES

Appendix 1: Manuscript Submission Guidelines: Journal of Clinical Psychology in Medical Settings: Springer

Manuscript Submission Guidelines: Journal of Clinical Psychology in Medical Settings: Springer

Instructions for Authors

General

In general, the journal follows the recommendations of the 2010 Publication Manual of the American Psychological Association (Sixth Edition), and it is suggested that contributors refer to this publication.

Manuscript Submission

Manuscripts, in English, should be submitted to the Editor via the Journal's web-based online manuscript submission and peer-review system: http://jocs.edmgr.com. In quiries regarding Journal policy and other such general topics should be sent to the Editor:

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Submit the original, including copies of all illustrations and tables.

Add continuous line numbering and page numbering to the manuscript.

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A title page is to be provided and should include

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- author's name (no degrees)
- author's affiliation
- suggested running head
- Declarations

The affiliation should comprise

- the department
- institution (usually university or company)
- city
- and state (or nation)

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• Funding (information that explains whether and by whom the research was supported)

• Conflicts of interest/Competing interests (include appropriate disclosures)

• Ethics approval (include appropriate approvals or waivers)

• Consent to participate (include appropriate consent statements)

• Consent for publication (consent statement regarding publishing an individual's data or image)

• Availability of data and material (data transparency)

• Code availability (software application or custom code)

• Authors' contributions

Please see the relevant sections in the submission guidelines for further information.

Abstract

- An abstract is to be provided, preferably no longer than 150 words.

Key Words

- A list of 4–5 key words is to be provided directly below the abstract. Key words should express the precise content of the manuscript, as they are used for indexing purposes.

References

List references alphabetically at the end of the paper and refer to them in the text by name and year in parentheses. References should include (in this order):

- last names and initials of all authors,
- year published
- title of article
- name of publication
- volume number
- and inclusive pages

The style and punctuation of the references should conform to strict APA style and follow guidelines of the Publication Manual of the American Psychological Association, Sixth Edition – illustrated by the following examples:

- Journal Article

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- Book

  Ray, R. (2006): *Chronic Pain and Family: A Clinical Perspective.* New York: Springer.

- Contribution to a Book

  Bleiberg, J., Ciulla, R., & Katz, B. L. (1991). Psychological components of rehabilitation programs for brain−injured and spinal−cord−injured patients. In J. J. Sweet, R. H. Rozensky, & S. M. Tovian (Eds.), *Handbook of clinical psychology in medical settings* (pp. 375−400). New York: Plenum Press.

Footnotes

- Footnotes should be avoided. When their use is absolutely necessary, footnotes should be numbered consecutively using Arabic numerals and should be typed at the bottom of the page to which they refer. Place a line above the footnote, so that it is set off from the text. Use the appropriate superscript numeral for citation in the text.

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- Tables should be numbered (with Arabic numerals) and referred to by number in the text. Each table should be typed on a separate page. Center the title above the table, and type explanatory footnotes (indicated by superscript lowercase letters) below the table.

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One author is assigned as Corresponding Author and acts on behalf of all co-authors and ensures that questions related to the accuracy or integrity of any part of the work are appropriately addressed.

The Corresponding Author is responsible for the following requirements:

- ensuring that all listed authors have approved the manuscript before submission, including the names and order of authors;
- managing all communication between the Journal and all co-authors, before and after publication;*
- providing transparency on re-use of material and mention any unpublished material (for example manuscripts in press) included in the manuscript in a cover letter to the Editor;
- making sure disclosures, declarations and transparency on data statements from all authors are included in the manuscript as appropriate (see above).

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In absence of specific instructions and in research fields where it is possible to describe discrete efforts, the Publisher recommends authors to include contribution statements in the work that specifies the contribution of every author in order to promote transparency. These contributions should be listed at the separate title page.

Examples of such statement(s) are shown below:

• Free text:

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by [full name], [full name] and [full name]. The first draft of the manuscript was written by [full name] and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Example: CRediT taxonomy:

• Conceptualization: [full name], …; Methodology: [full name], …; Formal analysis and investigation: [full name], …; Writing - original draft preparation: [full name, …]; Writing - review and editing: [full name], …; Funding acquisition: [full name], …; Resources: [full name], …; Supervision: [full name].

For **review articles** where discrete statements are less applicable a statement should be included who had the idea for the article, who performed the literature search and data analysis, and who drafted and/or critically revised the work.

For articles that are based primarily on the **student's dissertation or thesis**, it is recommended that the student is usually listed as principal author:

A Graduate Student's Guide to Determining Authorship Credit and Authorship Order, APA Science Student Council 2006

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The primary affiliation for each author should be the institution where the majority of their work was done. If an author has subsequently moved, the current address may additionally be stated. Addresses will not be updated or changed after publication of the article.

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Adding and/or deleting authors at revision stage are generally not permitted, but in some cases it may be warranted. Reasons for these changes in authorship should be explained. Approval of the change during revision is at the discretion of the Editor-in-Chief. Please note that journals may have individual policies on adding and/or deleting authors during revision stage.

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Authors should include the following statements (if applicable) in a separate section entitled "Compliance with Ethical Standards" when submitting a paper:

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- Research involving Human Participants and/or Animals
- Informed consent

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Interests that should be considered and disclosed but are not limited to the following:

Funding: Research grants from funding agencies (please give the research funder and the grant number) and/or research support (including salaries, equipment, supplies, reimbursement for attending symposia, and other expenses) by organizations that may gain or lose financially through publication of this manuscript.

Employment: Recent (while engaged in the research project), present or anticipated employment by any organization that may gain or lose financially through publication of this manuscript. This includes multiple affiliations (if applicable).

Financial interests: Stocks or shares in companies (including holdings of spouse and/or children) that may gain or lose financially through publication of this manuscript; consultation fees or other forms of remuneration from organizations that may gain or lose financially; patents or patent applications whose value may be affected by publication of this manuscript.

It is difficult to specify a threshold at which a financial interest becomes significant, any such figure is necessarily arbitrary, so one possible practical guideline is the following: "Any undeclared financial interest that could embarrass the author were it to become publicly known after the work was published."

Non-financial interests: In addition, authors are requested to disclose interests that go beyond financial interests that could impart bias on the work submitted for publication such as professional interests, personal relationships or personal beliefs (amongst others). Examples include, but are not limited to: position on editorial board, advisory board or board of directors or other type of management relationships; writing and/or consulting for educational purposes; expert witness; mentoring relations; and so forth.

Primary research articles require a disclosure statement. Review articles present an expert synthesis of evidence and may be treated as an authoritative work on a subject. Review articles therefore require a disclosure statement. Other article types such as editorials, book reviews, comments (amongst others) may, dependent on their content, require a disclosure statement. If you are unclear whether your article type requires a disclosure statement, please contact the Editor-in-Chief.

Please note that, in addition to the above requirements, funding information (given that funding is a potential conflict of interest (as mentioned above)) needs to be disclosed upon submission of the manuscript in the peer review system. This information will automatically be added to the Record of CrossMark, however it is **not added** to the manuscript itself. Under 'summary of requirements' (see below) funding information should be included in the '**Declarations**' section.

Summary of requirements

The above should be summarized in a statement and included on **a title page that is separate from the manuscript** with a section entitled "**Declarations**" when submitting a paper. Having all statements in one place allows for a consistent and unified review of the information by the Editor-in-Chief and/or peer reviewers and may speed up the handling of the paper. Declarations include Funding, Conflicts of interest/competing interests, Ethics approval, Consent, Data, Materials and/or Code availability and Authors' contribution statements. **Please use the title page for providing the statements.**

Once and if the paper is accepted for publication, the production department will put the respective statements in a distinctly identified section clearly visible for readers.

Please see the various examples of wording below and revise/customize the sample statements according to your own needs.

When all authors have the same (or no) conflicts and/or funding it is sufficient to use one blanket statement.

Provide "**Funding**" as a heading (**see template**)

- Partial financial support was received from [...]
- The research leading to these results received funding from […] under Grant Agreement No[…].
- This study was funded by […]
- This work was supported by […] (Grant numbers […] and […]

In case of no funding:

- The authors did not receive support from any organization for the submitted work.
- No funding was received to assist with the preparation of this manuscript.
- No funding was received for conducting this study.
- No funds, grants, or other support was received.

Provide "**Conflicts of interest/Competing interests**" as a header (**see template**)

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  Non-financial interests: Author C is an unpaid member of committee Z.

- **Financial interests:** The authors declare they have no financial interests.

  Non-financial interests: Author A is on the board of directors of Y and receives no compensation as member of the board of directors.

- **Financial interests:** Author A received a speaking fee from Y for Z. Author B receives a salary from association X. X where s/he is the Executive Director.

  Non-financial interests: none.

- **Financial interests:** Author A and B declare they have no financial interests. Author C has received speaker and consultant honoraria from Company M and Company N. Dr. C has received speaker honorarium and research funding from Company M and Company O. Author D has received travel support from Company O.

  Non-financial interests: Author D has served on advisory boards for Company M, Company N and Company O.

When authors have nothing to declare the following statement may be used:

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- All authors certify that they have no affiliations with or involvement in any organization or entity with any financial interest or non-financial interest in the subject matter or materials discussed in this manuscript.
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Research involving human participants, their data or biological material

Ethics approval

When reporting a study that involved human participants, their data or biological material, authors should include a statement that confirms that the study was approved (or granted exemption) by the appropriate institutional and/or national research ethics committee (including the name of the ethics committee) and certify that the study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. If doubt exists whether the research was conducted in accordance with the 1964 Helsinki Declaration or comparable standards, the authors must explain the reasons for their approach, and demonstrate that an independent ethics committee or institutional review board explicitly approved the doubtful aspects of the study. If a study was granted exemption from requiring ethics approval, this should also be detailed in the manuscript (including the reasons for the exemption).

Retrospective ethics approval

If a study has not been granted ethics committee approval prior to commencing, retrospective ethics approval usually cannot be obtained and it may not be possible to consider the manuscript for peer review. The decision on whether to proceed to peer review in such cases is at the Editor's discretion.

Ethics approval for retrospective studies

Although retrospective studies are conducted on already available data or biological material (for which formal consent may not be needed or is difficult to obtain) ethics approval may be required dependent on the law and the national ethical guidelines of a country. Authors should check with their institution to make sure they are complying with the specific requirements of their country.

Ethics approval for case studies

Case reports require ethics approval. Most institutions will have specific policies on this subject. Authors should check with their institution to make sure they are complying with the specific requirements of their institution and seek ethics approval where needed. Authors should be aware to secure informed consent from the individual (or parent or guardian if the participant is a minor or incapable) See also section on **Informed Consent**.

Cell lines

If human cells are used, authors must declare in the manuscript: what cell lines were used by describing the source of the cell line, including when and from where it was obtained, whether the cell line has recently been authenticated and by what method. If cells were bought from a life science company the following need to be given in the manuscript: name of company (that provided the cells), cell type, number of cell line, and batch of cells.

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Further information is available from the International Cell Line Authentication Committee (ICLAC).

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Examples:

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Cell Line: RST307 cell line **RRID:CVCL_C321**

Antibody: Luciferase antibody DSHB Cat# LUC-3, **RRID:AB_2722109**

Plasmid: mRuby3 plasmid **RRID:Addgene_104005**

Software: ImageJ Version 1.2.4 **RRID:SCR_003070**

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Clinical Trial Registration

The World Health Organization (WHO) definition of a clinical trial is "any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes". The WHO defines health interventions as "A health intervention is an act performed for, with or on behalf of a person or population whose purpose is to assess, improve, maintain, promote or modify health, functioning or health conditions" and a health-related outcome is generally defined as a change in the health of a person or population as a result of an intervention.

To ensure the integrity of the reporting of patient-centered trials, authors must register prospective clinical trials (phase II to IV trials) in suitable publicly available repositories. For example www.clinicaltrials.gov or any of the primary registries that participate in the WHO International Clinical Trials Registry Platform.

The trial registration number (TRN) and date of registration should be included as the last line of the manuscript abstract.

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Randomised trials (CONSORT) and Study protocols (SPIRIT)

Observational studies (STROBE)

Systematic reviews and meta-analyses (PRISMA) and protocols (Prisma-P)

Diagnostic/prognostic studies (STARD) and (TRIPOD)

Case reports (CARE)

Clinical practice guidelines (AGREE) and (RIGHT)

Qualitative research (SRQR) and (COREQ)

Animal pre-clinical studies (ARRIVE)

Quality improvement studies (SQUIRE)

Economic evaluations (CHEERS)

Summary of requirements

The above should be summarized in a statement and placed in a 'Declarations' section before the reference list under a heading of 'Ethics approval'.

Examples of statements to be used when ethics approval has been obtained:

• All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the Bioethics Committee of the Medical University of A (No. ...).

• This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of University B (Date.../No. ...).

• Approval was obtained from the ethics committee of University C. The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

• The questionnaire and methodology for this study was approved by the Human Research Ethics committee of the University of D (Ethics approval number: ...).

Examples of statements to be used for a retrospective study:

• Ethical approval was waived by the local Ethics Committee of University A in view of the retrospective nature of the study and all the procedures being performed were part of the routine care.

• This research study was conducted retrospectively from data obtained for clinical purposes. We consulted extensively with the IRB of XYZ who determined that our study did not need ethical approval. An IRB official waiver of ethical approval was granted from the IRB of XYZ.

• This retrospective chart review study involving human participants was in accordance with the ethical standards of the institutional and national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The Human Investigation Committee (IRB) of University B approved this study.

Examples of statements to be used when no ethical approval is required/exemption granted:

• This is an observational study. The XYZ Research Ethics Committee has confirmed that no ethical approval is required.

• The data reproduced from Article X utilized human tissue that was procured via our Biobank AB, which provides de-identified samples. This study was reviewed and deemed exempt by our XYZ Institutional Review Board. The BioBank protocols are in accordance with the ethical standards of our institution and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Authors are responsible for correctness of the statements provided in the manuscript. See also Authorship Principles. The Editor-in-Chief reserves the right to reject submissions that do not meet the guidelines described in this section.

Informed consent

All individuals have individual rights that are not to be infringed. Individual participants in studies have, for example, the right to decide what happens to the (identifiable) personal data gathered, to what they have said during a study or an interview, as well as to any photograph that was taken. This is especially true concerning images of vulnerable people (e.g. minors, patients, refugees, etc) or the use of images in sensitive contexts. In many instances authors will need to secure written consent before including images.

Identifying details (names, dates of birth, identity numbers, biometrical characteristics (such as facial features, fingerprint, writing style, voice pattern, DNA or other distinguishing characteristic) and other information) of the participants that were studied should not be published in written descriptions, photographs, and genetic profiles unless the information is essential for scholarly purposes and the participant (or parent/guardian if the participant is a minor or incapable or legal representative) gave written informed consent for publication. Complete anonymity is difficult to achieve in some cases. Detailed descriptions of individual participants, whether of their whole bodies or of body sections, may lead to disclosure of their identity. Under certain circumstances consent is not required as long as information is anonymized and the submission does not include images that may identify the person.

Informed consent for publication should be obtained if there is any doubt. For example, masking the eye region in photographs of participants is inadequate protection of anonymity. If identifying characteristics are altered to protect anonymity, such as in genetic profiles, authors should provide assurance that alterations do not distort meaning.

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• Images such as x rays, laparoscopic images, ultrasound images, brain scans, pathology slides unless there is a concern about identifying information in which case, authors should ensure that consent is obtained.

• Reuse of images: If images are being reused from prior publications, the Publisher will assume that the prior publication obtained the relevant information regarding consent. Authors should provide the appropriate attribution for republished images.

Consent and already available data and/or biologic material

Regardless of whether material is collected from living or dead patients, they (family or guardian if the deceased has not made a pre-mortem decision) must have given prior written consent. The aspect of confidentiality as well as any wishes from the deceased should be respected.

Data protection, confidentiality and privacy

When biological material is donated for or data is generated as part of a research project authors should ensure, as part of the informed consent procedure, that the participants are made aware what kind of (personal) data will be processed, how it will be used and for what purpose. In case of data acquired via a biobank/biorepository, it is possible they apply a broad consent which allows research participants to consent to a broad range of uses of their data and samples which is

regarded by research ethics committees as specific enough to be considered “informed”. However, authors should always check the specific biobank/biorepository policies or any other type of data provider policies (in case of non-bio research) to be sure that this is the case.

Consent to Participate

For all research involving human subjects, freely-given, informed consent to participate in the study must be obtained from participants (or their parent or legal guardian in the case of children under 16) and a statement to this effect should appear in the manuscript. In the case of articles describing human transplantation studies, authors must include a statement declaring that no organs/tissues were obtained from prisoners and must also name the institution(s)/clinic(s)/department(s) via which organs/tissues were obtained. For manuscripts reporting studies involving vulnerable groups where there is the potential for coercion or where consent may not have been fully informed, extra care will be taken by the editor and may be referred to the Springer Nature Research Integrity Group.

Consent to Publish

Individuals may consent to participate in a study, but object to having their data published in a journal article. Authors should make sure to also seek consent from individuals to publish their data prior to submitting their paper to a journal. This is in particular applicable to case studies. A consent to publish form can be found

here. (Download docx, 36 kB)

Summary of requirements

The above should be summarized in a statement and placed in a ‘Declarations’ section before the reference list under a heading of ‘Consent to participate’ and/or ‘Consent to publish’. Other declarations include Funding, Conflicts of interest/competing interests, Ethics approval, Consent, Data and/or Code availability and Authors’ contribution statements.

Please see the various examples of wording below and revise/customize the sample statements according to your own needs.

Sample statements for **"Consent to participate"**:

Informed consent was obtained from all individual participants included in the study.

Informed consent was obtained from legal guardians.

Written informed consent was obtained from the parents.

Verbal informed consent was obtained prior to the interview.

Sample statements for **“Consent to publish”**:

The authors affirm that human research participants provided informed consent for publication of the images in Figure(s) 1a, 1b and 1c.

The participant has consented to the submission of the case report to the journal.

Patients signed informed consent regarding publishing their data and photographs.

Sample statements if identifying information about participants is available in the article:

Additional informed consent was obtained from all individual participants for whom identifying information is included in this article.

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Appendix 2: Example Search Strategy

1. “post traumatic growth”
2. “personal growth”
3. “positive growth”
4. “psychological growth”
5. “perceiv* growth”
6. “perceiv* benefits”
7. “benefit finding”
8. “stress related growth”
9. “adversarial growth”
10. “sense making”
11. “meaning making”
12. “flourishing”
13. “neurodegenerative diseas*”
14. “neurodegeneration”
15. “dementia”
16. “Parkinson’s disease”
17. “Alzheimer’s disease”
18. “Huntington’s disease”
19. “Multiple Sclerosis”
20. “Motor Neuron* Disease”
21. “Amyotrophic Lateral Sclerosis”
22. “Lewy Body Disease”
23. “Creutzfeldt-Jakob Disease”

1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 AND 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23

Appendix 3: Inclusion and Exclusion Criteria

Study Parameters	Inclusion Criteria	Exclusion Criteria
Study Type	Peer-reviewed primary research studies.	Unpublished theses; systematic & literature reviews; posters; case studies; non-peer reviewed articles; opinion pieces; commentaries; book chapters; book reviews.
Sample / Population	People aged over 18 and living with one of the identified Neurodegenerative conditions (i.e., Huntington's Disease, Parkinson's Disease, Alzheimer's Disease, dementia, Multiple Sclerosis, Motor Neurone Disease / Amyotrophic Lateral Sclerosis, Lewy Body Disease, Creutzfeldt-Jakob Disease). Residing in a Western country. All genders, ages, disease durations, cultural backgrounds etc.	Participants aged under 18 and living with a condition not listed, such as Stroke. Participants from a Non-Western country. Studies focussing on the experiences of carers.
Study Focus	Studies that directly explore the experience of PTG (or one of the defined related terms) in relation to living with a Neurodegenerative condition.	Studies which focussed on the effectiveness of a specific intervention.
Methodology	Studies using quantitative, qualitative and mixed methodology approaches to data collection and analysis.	No exclusions in relation to methodology.
Date	Studies dated after 1995.	Studies dated prior to 1995.
Language	English or translated into English only.	Not written or translated into English.

Appendix 4: Quality Assessment Tool Assessment Criteria – The QATSDD

Criteria	0 = Not at all	1 = Very slightly	2 = Moderately	3 = Complete
Explicit theoretical framework	No mention at all.	Reference to broad theoretical basis.	Reference to a specific theoretical basis.	Explicit statement of theoretical framework and/or constructs applied to the research.
Statement of aims/objectives in main body of report	No mention at all.	General reference to aim/objective at some point in the report including abstract.	Reference to broad aims/objectives in main body of report.	Explicit statement of aims/objectives in main body of report.
Clear description of research setting	No mention at all.	General description of research area and background, e.g. 'in primary care'.	General description of research problem in the target population, e.g. 'among GPs in primary care'.	Specific description of the research problem and target population in the context of the study, e.g. nurses and doctors from GP practices in the east midlands.
Evidence of sample size considered in terms of analysis	No mention at all.	Basic explanation for choice of sample size. Evidence that size of the sample has been considered in study design.	Evidence of consideration of sample size in terms of saturation/information redundancy or to fit generic analytical requirements.	Explicit statement of data being gathered until information redundancy/saturation was reached or to fit exact calculations for analytical requirements.
Representative sample of target group of a reasonable size	No statement of target group.	Sample is limited but represents some of the target group or representative but very small.	Sample is somewhat diverse but not entirely representative, e.g. inclusive of all age groups, experience but only one workplace. Requires discussion of target population to determine what sample is required to be representative.	Sample includes individuals to represent a cross section of the target population, considering factors such as experience, age and workplace.
Description of procedure for data collection	No mention at all.	Very basic and brief outline of data collection procedure, e.g. 'using a questionnaire distributed to staff'.	States each stage of data collection procedure but with limited detail, or states some stages in details but omits others.	Detailed description of each stage of the data collection procedure, including when, where and how data were gathered.
Rationale for choice of data collection tool(s)	No mention at all.	Very limited explanation for choice of data collection tool(s).	Basic explanation of rationale for choice of data collection tool(s), e.g. based on use in a prior similar study.	Detailed explanation of rationale for choice of data collection tool(s), e.g. relevance to the study aims and assessments of tool quality either statistically, e.g. for reliability & validity, or relevant qualitative assessment.
Detailed recruitment data	No mention at all.	Minimal recruitment data, e.g. no. of questionnaire sent and no. returned.	Some recruitment information but not complete account of the recruitment process, e.g. recruitment figures but no information on strategy used.	Complete data regarding no. approached, no. recruited, attrition data where relevant, method of recruitment.
Statistical assessment of reliability and validity of measurement tool(s) (Quantitative only)	No mention at all.	Reliability and validity of measurement tool(s) discussed, but not statistically assessed.	Some attempt to assess reliability and validity of measurement tool(s) but insufficient, e.g. attempt to establish test–retest reliability is unsuccessful but no action is taken.	Suitable and thorough statistical assessment of reliability and validity of measurement tool(s) with reference to the quality of evidence as a result of the measures used.
Fit between stated research question and method of data collection (Quantitative)	No research question stated.	Method of data collection can only address some aspects of the research question.	Method of data collection can address the research question but there is a more suitable alternative that could have been used or used in addition.	Method of data collection selected is the most suitable approach to attempt answer the research question
Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative)	No research question stated.	Structure and/or content only suitable to address the research question in some aspects or superficially.	Structure & content allows for data to be gathered broadly addressing the stated research question(s) but could benefit from greater detail.	Structure & content allows for detailed data to be gathered around all relevant issues required to address the stated research question(s).
Fit between research question and method of analysis	No mention at all.	Method of analysis can only address the research question basically or broadly.	Method of analysis can address the research question but there is a more suitable alternative that could have been used or used in addition to offer greater detail.	Method of analysis selected is the most suitable approach to attempt answer the research question in detail, e.g. for qualitative IPA preferable for experiences vs. content analysis to elicit frequency of occurrence of events, etc.
Good justification for analytical method selected	No mention at all.	Basic explanation for choice of analytical method	Fairly detailed explanation of choice of analytical method.	Detailed explanation for choice of analytical method based on nature of research question(s).
Assessment of reliability of analytical process (Qualitative only)	No mention at all.	More than one researcher involved in the analytical process but no further reliability assessment.	Limited attempt to assess reliability, e.g. reliance on one method.	Use of a range of methods to assess reliability, e.g. triangulation, multiple researchers, varying research backgrounds.
Evidence of user involvement in design	No mention at all.	Use of pilot study but no involvement in planning stages of study design.	Pilot study with feedback from users informing changes to the design.	Explicit consultation with steering group or statement or formal consultation with users in planning of study design.
Strengths and limitations critically discussed	No mention at all.	Very limited mention of strengths and limitations with omissions of many key issues.	Discussion of some of the key strengths and weaknesses of the study but not complete.	Discussion of strengths and limitations of all aspects of study including design, measures, procedure, sample & analysis.

Appendix 5: Systematic Review Data Extraction Tool

Reference:	
Aims	
Participant Characteristics (including *n*)	
Sampling	
Location / Setting	
Methodology	
Analysis	
Service-User Involvement	
Summary of key outcomes relating to PTG	
Key Limitations	

Appendix 6: Manuscript Submission Guidelines: Dementia: SAGE

Manuscript Submission Guidelines: Dementia: SAGE

This Journal is a member of the Committee on Publication Ethics.

Please read the guidelines below then visit the Journal's submission site http://mc.manuscriptcentral.com/dementia to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.

Only manuscripts of sufficient quality that meet the aims and scope of Dementia will be reviewed.

There are no fees payable to submit or publish in this journal.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere. Please see our guidelines on prior publication and note that ***Dementia* may accept submissions of papers that have been posted on pre-print servers;** please alert the Editorial Office when submitting (contact details are at the end of these guidelines) and include the DOI for the preprint in the designated field in the manuscript submission system. Authors should not post an updated version of their paper on the preprint server while it is being peer reviewed for possible publication in the journal. If the article is accepted for publication, the author may re-use their work according to the journal's author archiving policy. If your paper is accepted, you must include a link on your preprint to the final version of your paper.

If you have any questions about publishing with SAGE, please visit the SAGE Journal Solutions Portal

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Dementia, please ensure you have read the Aims & Scope.

1.2 Article Types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia. Biomedical and overly clinical research articles will not be accepted.

Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

The journal also publishes book reviews. We send out a list of books to review twice a year in September and March.

If you would like to receive this list please e-mail Sarah Campbell, Book Review Editor at Sarah.Campbell@MMU.ac.uk and you will be added to our reviewer list. We welcome suggestions of books to review at any time. Also, if you have read a book that you think would be of interest to the journal and would like to review it, we also welcome unsolicited contributions.

Book reviews are usually around 1000 words in length but it will vary depending on the book. Providing a book review is not a guarantee of publication.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

2. Editorial policies

2.1 Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission,
- The reviewer should not have recently collaborated with any of the authors,
- Reviewer nominees from the same institution as any of the authors are not permitted.

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Any acknowledgements should be placed on the title page. Your main text should include a Declaration of Conflicting Interests (if applicable), any notes and your References but should be completely blinded.

2.3.1 Third party submissions

Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

- Disclose this type of editorial assistance – including the individual's name, company and level of input
- Identify any entities that paid for this assistance
- Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

Where appropriate, SAGE reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

2.4 Funding

Dementia requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

It is the policy of Dementia to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'. For guidance on conflict of interest statements, please see the ICMJE recommendations here.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient's actual written informed consent with your article, as this in itself breaches the patient's confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for example in a patient's hospital record. The confirmatory letter may be uploaded with your submission as a separate file.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants.

At SAGE we are committed to facilitating openness, transparency and reproducibility of research. Where relevant, The Journal encourages authors to share their research data in a suitable public repository subject to ethical considerations and where data is included, to add a data accessibility statement in their manuscript file. Authors should also follow data citation principles. For more information please visit the SAGE Author Gateway, which includes information about SAGE's partnership with the data repository Figshare.

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

Dementia and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

3.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit the SAGE Author Gateway.

3.3 Open access and author archiving

Dementia offers optional open access publishing via the SAGE Choice programme. For more information please visit the SAGE Choice website. For information on funding body compliance, and depositing your article in repositories, please visit SAGE Publishing Policies on our Journal Author Gateway.

4. Preparing your manuscript for submission

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

4.2 Language

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. dements). Language that might be deemed sexist or racist should not be used. All submissions should avoid the use of insensitive or demeaning language. In particular, authors should use 'dementia-friendly' language in positioning people living with dementia in their article and avoid using pejorative terms such as 'demented' or 'suffering from dementia'.

Please also consider how you are using abbreviations in your submission. Whilst QoL (for quality of life) and MMSE (for Mini-mental State Examination) may have common usage, please try to avoid unnecessary abbreviations in the submission of your manuscript, such as PWD (for people with dementia) and abbreviations that detract from the overall flow of the manuscript.

Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

Useful websites to refer to for guidance

We recommend that authors refer to the Dementia Engagement and Empowerment Project (DEEP) guidance which was developed by people living with dementia and offers a range of advice and support, including writing dementia-friendly information.

Alternatively, Alzheimer's Australia sets out guidelines for dementia-friendly language, as do the Alzheimer Society of Canada, both of which are useful for guidance.

4.3 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.4 Supplemental material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

4.5 Reference style

Dementia adheres to the APA reference style. View the APA guidelines to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

5. Submitting your manuscript

Dementia is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit http://mc.manuscriptcentral.com/dementia to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

Book reviews must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Sarah Campbell Sarah.Campbell@MMU.ac.uk

5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.

The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID iD please follow this link to create one or visit our ORCID homepage to learn more.

5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. The affiliation listed in the manuscript should be the institution where the research was conducted. If an author has moved to a new institution since completing the research, the new affiliation can be included in a manuscript note at the end of the paper. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

5.3 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway.

6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be made available to the corresponding author via our editing portal SAGE Edit or by email, and corrections should be made directly or notified to us promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

6.2 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

6.3 Access to your published article

SAGE provides authors with online access to their final article.

6.4 Promoting your article

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the Promote Your Article page on the Gateway for tips and advice.

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Dementia editorial office as follows:

dem.pra@sagepub.com

Appendix 7: Original Ethical Approval

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Dr Sarah Butchard
Doctorate in Clinical Psychology
University of Liverpool, Whelan Building
Brownlow Hill, Liverpool
L69 3GB

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

03 July 2020

Dear Dr Butchard

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**The experience of post-traumatic growth in people living with dementia: A q-methodology study**
IRAS project ID:	**274903**
Protocol number:	**UoL001516 5889**
REC reference:	**20/SC/0176**
Sponsor	**University of Liverpool**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **274903**. Please quote this on all correspondence.

Yours sincerely,

Maeve Ip Groot Bluemink
Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Mr Alex Astor*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Poster 1]	2	22 May 2020
Copies of advertisement materials for research participants [Poster 2]	2	22 May 2020
Copies of advertisement materials for research participants [Poster 3]	2	22 May 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor Insurance]	2	31 July 2019
HRA Schedule of Events	1	20 March 2020
Interview schedules or topic guides for participants [Interview Protocol]	2	04 June 2020
IRAS Application Form [IRAS_Form_11032020]		11 March 2020
Letter from sponsor [Sponsorship Approval Letter]	1	12 February 2020
Organisation Information Document [Organisation Information Document]	1	17 February 2020
Other [Letter to REC re: Amendments]		25 March 2020
Other [GCP Certificate]	1	17 May 2020
Other [REC Amendments Table]	1	22 May 2020
Other [REC Amendments Table - Part 2]	1	04 June 2020
Other [DClin Research Review Committee Approval Letter]	1	27 August 2019
Participant consent form [Phase 1 Consent Form]	4	04 June 2020
Participant consent form [Phase 2 Consent Form]	4	04 June 2020
Participant information sheet (PIS) [Participant Information Sheet]	4	04 June 2020
Research protocol or project proposal [Research Protocol]	5	22 May 2020
Summary CV for Chief Investigator (CI) [CI Research CV]	1	07 October 2019
Summary CV for student [Trainee Research CV]	1	24 February 2020
Summary CV for supervisor (student research) [Secondary Supervisor CV]	1	20 March 2020

IRAS project ID	274903

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
There will be one study site type.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.	No external funding has been sought.	A local collaborator is expected at site.	Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtaina Letter of Access based on standard DBS checks and occupational health clearance.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix 8: Ethical Approval for Amendments

Health Research Authority

South Central - Oxford C Research Ethics Committee
Level 3, Block B
Whitefriars Building
Lewins Mead
Bristol
BS1 2NT

Tel: 0207 104 8379

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

28 July 2020

Miss Charlotte Cooper
Doctorate in Clinical Psychology
University of Liverpool, Whelan Building
Brownlow Hill, Liverpool
L69 3GB

Dear Miss Cooper

Study title:	**The experience of post-traumatic growth in people living with dementia: A q-methodology study**
REC reference:	**20/SC/0176**
Protocol number:	**UoL001516 5889**
Amendment number:	**UoL001516 Amendment 1**
Amendment date:	**15 June 2020**
IRAS project ID:	**274903**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [274903_UoL001516 Amendment 1_15Jun2020_Locked21Jul20_100422]	1.1	21 July 2020
Other [Recruitment Poster]	3	30 June 2020
Participant consent form [Consent Form]	5	16 June 2020
Participant information sheet (PIS) [Participant Information Sheet]	6	27 July 2020
Research protocol or project proposal [ResearchProposal_V5_COVIDAmend_Tracked]	5.0	16 June 2020

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS Project ID - 274903:	**Please quote this number on all correspondence**

Yours sincerely

Dr Lee Potiphar
Chair

E-mail: oxfordc.rec@hra.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Miss Charlotte Cooper*

South Central - Oxford C Research Ethics Committee

Attendance at Sub-Committee of the REC in correspondence

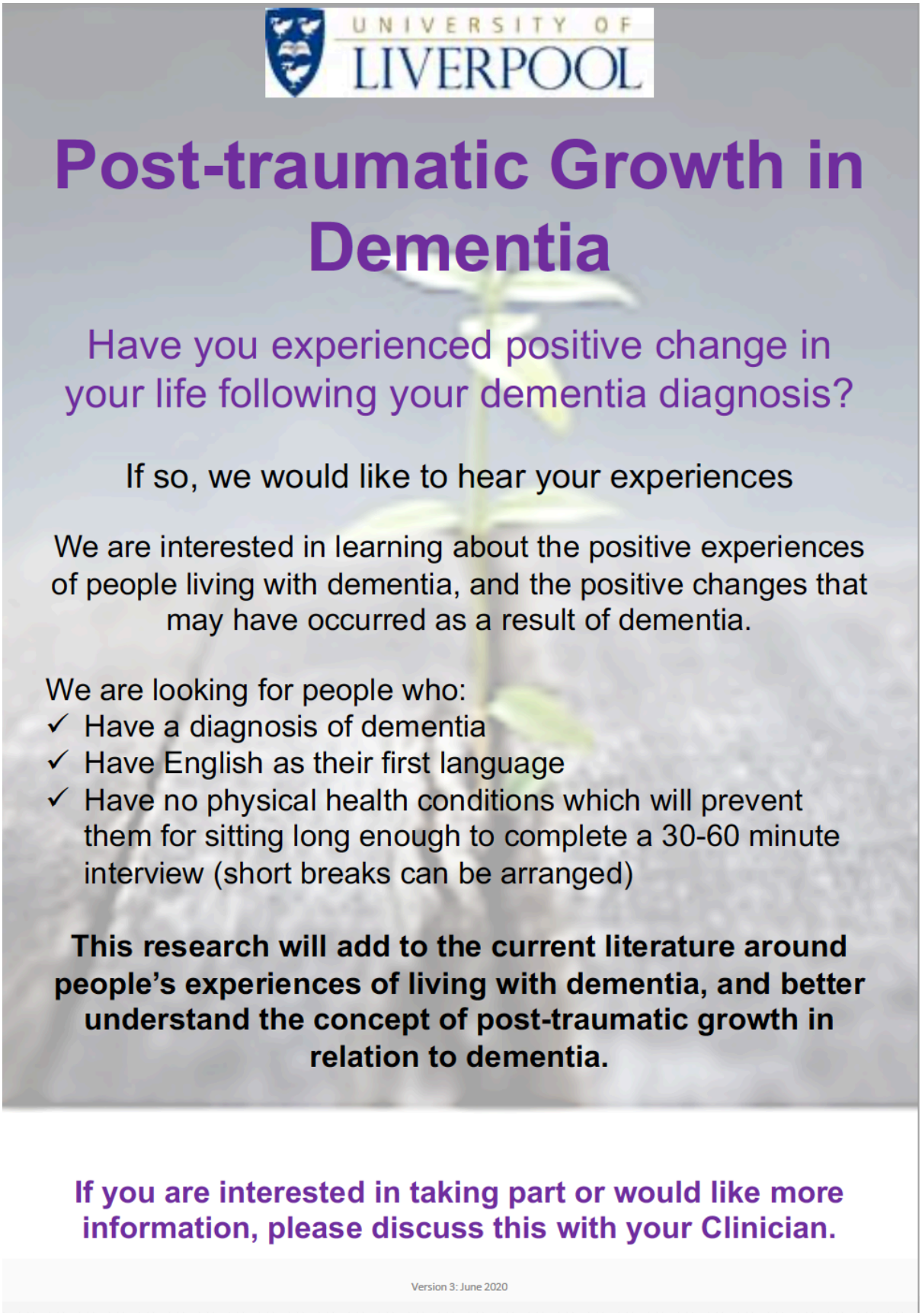
Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Lee Potiphar	Senior Lecturer in Adult Nursing and Senior Tutor	Yes	Chair
Dr David Scott	Lecturer	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Miss Theodora Chortara	Approvals Administrator

Appendix 9: Research Poster (NHS)



Appendix 10: Research Poster (Third Sector)

Appendix 11: Participant Information Sheet

DClin Psychology Programme
School of Psychology
Whelan Building, Quadrangle
Brownlow Hill
LIVERPOOL
L69 3GB
Tel: 0151 794 5530/5534/5877
0151 795 5446
www.liverpool.ac.uk/psychology/study/doctorate

Participant Information Sheet: Post-traumatic Growth in Dementia

We would like to invite you to take part in the following research study:

'The experience of post-traumatic growth in people living with dementia: A Grounded Theory study'

Please read the following information clearly. Take time to decide whether or not you would like to take part. You can change your mind at any time.

What is the purpose of the study?

Recent research has focused on the concept of growth following dementia diagnosis, suggesting people might not just live well *in spite* of dementia, but *because* of it. However, receiving a diagnosis of dementia has been identified as being traumatic for some. Traumatic experiences can shatter people's assumptions about life, but through the restructuring of these assumptions, it is thought people can be positively transformed. This has been defined as post-traumatic growth. It is therefore possible that dementia itself could stimulate post-traumatic growth amongst some individuals.

Researchers are the University of Liverpool would like to find out whether people living with dementia have experienced post-traumatic growth following their diagnosis, and what this may look like to them.

Who is sponsoring the research?

The research is being undertaken by a full-time doctorate student as part of their clinical psychology training. The research is sponsored by the University of Liverpool.

Do I have to take part?

No – your participation is always voluntary. You can stop being part of the study at any time, without giving a reason, by telephoning a member of the research team. If you withdraw before the data has been analysed, any information held about you by the research team will be destroyed. If you withdraw after the analysis has taken place, we will need to keep the information about you that we have collected. Withdrawal will not impact upon the service you may receive from the older adult community mental health team. If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

UNIVERSITY OF LIVERPOOL

Who can I contact about the study?
For more information or to arrange a research appointment, please contact the researcher:

Charlotte Cooper (Trainee Clinical Psychologist)
Office Tel: 0151 795 5446

What will I have to do?
The study involves you taking part in one 30-60 minute interview about your experiences of living with dementia.

How long will it take?	Approximately 30-60 minutes
Where will the research appointment take place?	At your home or the community mental health team clinic. During the COVID pandemic, appointments will take place over Zoom or telephone.
Who will be involved?	You and the researcher. A carer can be present if you would like.
What will I have to do?	The researcher will talk to you about the term post-traumatic growth and your diagnosis of dementia. The conversation will be audio-recorded.

How will we use information about you?
We will need to use information from you for this research project.

This information will include your initials, name, age, contact details, and details of your diagnosis. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

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Where can you find out more about how your information is used?
You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/ or www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team; or
- by ringing us on 0151 795 5446.

Will my taking part in the study be kept confidential?
If you have been recruited through the Older Adult Mental Health team, your Care Co-ordinator will be informed that you have decided to take part in the study. Otherwise, all information about you will be kept strictly confidential.

- We will keep all information about you safe and secure, and your name and address will be removed from any information about you which leaves the university.
- The audio-recording of your interview will be accessible by members of the research team. It will also be available to a transcriber who will type up the content of the interview. The transcriber will be university-approved and will be required to sign a confidentiality agreement. Once the interview has been typed up, the audio copy of your interview will be destroyed.
- If your interview takes place over Zoom, the researcher will use a Dictaphone to record only your voice. This will mean that your picture will not be recorded in order to ensure confidentiality. The researcher will make you aware of when the recording has started and ended.
- All data will be held on a password-protected computer on a secure and encrypted server.
- All identifiable data will be destroyed once the research has been written up. All non-identifiable data will be held for up to 5 years at the University of Liverpool and then destroyed.

What will happen to the results of the study?
All participants will receive a feedback letter giving a summary of the research findings. The results will be included in a thesis report that will be submitted to the University of Liverpool by the researcher as part of their clinical training.

The thesis report will also be submitted for publication in a peer-reviewed journal to share the findings with other professionals. The research team also hope to be able to present the results at a national conference and a local service user forum.

All data used in reports, publications and presentations will be anonymised.

How will I be compensated for my time?
If you travel to participate in the research, we will reimburse your mileage or public transport costs.

What are the possible benefits of taking part?
Although taking part in the study may not help you directly, some people may find sharing their experiences to be worthwhile and rewarding.

It is hoped that the findings will contribute to our understanding of what it means to "live well with dementia" in the context of post-traumatic growth.

What are the possible drawbacks or risks of taking part?

- **It may be upsetting for you**
  Discussing your experiences of receiving a diagnosis and living with dementia can be very emotional. This is understandable, and something you may want to consider when thinking about whether or not you wish to take part in this study.

  The researcher is a Trainee Clinical Psychologist employed by Mersey Care NHS Trust who is trained to support people in distress. Therefore, appropriate emotional support will be offered to you during the tasks if you become distressed. If required, appropriate additional support can be made available after you have completed the tasks, through your older adult community mental health team. Details of support organisations will also be offered to all participants.

- **There may be concerns about your safety or someone else's**
  Talking about your personal experiences of living with dementia may raise concerns about your safety or someone else's. The researcher has a duty of care to report safeguarding concerns, which will mean breaking confidentiality even if you decide to withdraw from the study. Where possible, the researcher will tell you if they need to do this.

- **Your ability to take part may change over time**
  If you wish to take part, you will need to be able to complete an audio-recorded interview. Your dementia diagnosis may mean that your ability to take part in this task may change over time. This means that you may agree to take part but may be unable to do so at the research appointment. The researcher will ask you some questions at your research appointment to ensure your understanding of the research and assess your ability to take part.

What if I have a concern or a problem with the research?
If you have a concern, please contact the researcher or the research supervisor:

Charlotte Cooper (researcher) or Dr Sarah Butchard (research supervisor)
Doctorate in Clinical Psychology
University of Liverpool
Whelan Building
Brownlow Hill
Liverpool
L69 3GB
Tel: 0151 795 5446

Appendix 12: Consent Form

UNIVERSITY OF LIVERPOOL

DClin Psychology Programme
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L69 3GB
Tel: 0151 794 5530/5534/5877
0151 795 5446
www.liverpool.ac.uk/psychology/study/doctorate

Participant ID:

Consent Form: Post-traumatic Growth in Dementia

Research Title: The experience of post-traumatic growth in people living with dementia: A Grounded Theory study

Research Team: Charlotte Cooper (Researcher); Dr Sarah Butchard (Primary Supervisor); Dr Chris Clarke (Secondary Supervisor)

Please read the statements below and tick the box if you agree.

1. I confirm that I have read and understood the attached information sheet (dated: July 2020; version 6) and have had the opportunity to consider the information and ask any questions.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. If I choose to withdraw I understand that my medical care or legal rights will not be affected.	☐
3. I understand that all data collected about me will be anonymised before it is submitted for publication in any peer-reviewed journals or presented at conferences.	☐
4. If I decide to withdraw from the study after my data has been analysed, I agree for this anonymised data to still be used in analysis.	☐
5. I understand that this interview will be audio recorded and transcribed. I understand that at this stage, all identifiable information will be removed and replaced with a pseudonym.	☐
6. I understand all identifiable information gathered during my interview will be destroyed once the research has written up, and that all non-identifiable information will be held by the University of Liverpool for 5 years and then destroyed.	☐
7. I understand that the information collected may be used to support other research in the future.	☐
8. I agree to take part in this study, and in doing so understand that I will take part in an interview where I will be asked about my experiences of living with dementia.	☐

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of researcher	Date	Signature

NHS Mersey Care NHS Foundation Trust

NHS Tees, Esk and Wear Valleys NHS Foundation Trust

deep The UK Network of Dementia Voices

Appendix 13: Interview Topic Guide

Demographics

- Gender
- Age
- Type of dementia
- Age at diagnosis
- Previous trauma
- English first language
- Medical conditions which may prevent them from taking part in the research

Can you tell me a little bit about the process of how you were diagnosed with dementia?

Prompts:

- *What was your response when you were diagnosed?*
- *What was the response of those around you?*
- *What did you think about the diagnosis?*
- *What were your initial thoughts and feelings about the diagnosis?*

How has life changed for you since your diagnosis of dementia?

Prompts:

- *Thinking about your thoughts and feelings when you were first diagnosed, and your thoughts and feelings now, has that changed at all, and if so, how?*
- *What positive experiences have you had since your diagnoses? How did that make you feel?*
- *What negative experiences have you had since your diagnosis? How did that make you feel?*
- *You explained you find X difficult, how have you learnt to manage that?*

Would you describe yourself as someone who "lives well" with dementia?

Prompts:

- *What does "living well" with dementia mean to you?*
- *How do you feel about that term?*

Who has been the most helpful to you since your diagnosis?

Prompts:

- *Have you found anybody new who has helped you who maybe wasn't in your life before?*
- *How has your support network changed since your diagnosis?*

What has been the most helpful to you since your diagnosis?

Prompts:

- *Have you found new things helpful that maybe weren't in your life before?*

- *Have you discovered any new hobbies?*
- *What are your interests? Are they different to the interests you had before your diagnosis?*

What do you consider your strengths to be now? Are they different to the strengths you may have identified before your diagnosis?

Prompts:
- *What are you good at?*
- *Is that something you've always been good at?*

What do you value most about yourself now?

Prompts:
- *What are your good qualities?*
- *If I asked someone close to you, what do you think they would value most in you?*

Has your outlook on life changed since your diagnosis?

Prompts:
- *How do you view your past?*
- *How do you view your future?*
- *Have you learnt any 'life lessons' since your diagnosis?*

With your experience of living with dementia, what do you think is important for those who have been newly diagnosed to know?

Prompts:
- *What advice would you give to those who have recently been diagnosed?*

Is there anything else you think I should know or anything I need to understand about your experience?

Updated Interview Topic Guide

Demographics

- Gender
- Age
- Type of dementia
- Age at diagnosis
- Previous trauma
- English first language
- Medical conditions which may prevent them from taking part in the research

Can you tell me a little bit about the process of how you were diagnosed with dementia?

Prompts:

- *What was your response when you were diagnosed?*
- *What was the response of those around you?*
- *What did you think about the diagnosis?*
- *What were your initial thoughts and feelings about the diagnosis?*
- *Can you remember how you felt for the first few weeks / months after diagnosis?*

How has life changed for you since your diagnosis of dementia?

Prompts:

- *Thinking about your thoughts and feelings when you were first diagnosed, and your thoughts and feelings now, has that changed at all, and if so, how?*
- *What positive experiences have you had since your diagnoses? How did that make you feel?*
- *What negative experiences have you had since your diagnosis? How did that make you feel?*
- *You explained you find X difficult, how have you learnt to manage that?*
- *If there has been a change, can you identify the point when your life changed? What do you think motivated this change?*

Would you describe yourself as someone who "lives well" with dementia?

Prompts:

- *What does "living well" with dementia mean to you?*
- *How do you feel about that term?*

Who has been the most helpful to you since your diagnosis?

Prompts:

- *Have you found anybody new who has helped you who maybe wasn't in your life before?*
- *How has your support network changed since your diagnosis?*
- *What is your relationship like with clinical services?*

What has been the most helpful to you since your diagnosis?

Prompts:

- *Have you found new things helpful that maybe weren't in your life before?*
- *Have you discovered any new hobbies?*
- *What are your interests? Are they different to the interests you had before your diagnosis?*
- *Have you done anything that has surprised you?*

What do you consider your strengths to be now? Are they different to the strengths you may have identified before your diagnosis?

Prompts:

- *What are you good at?*
- *Is that something you've always been good at?*

What do you value most about yourself now?

Prompts:

- *What are your good qualities?*
- *If I asked someone close to you, what do you think they would value most in you?*

Has your outlook on life changed since your diagnosis?

Prompts:

- *How do you view your past?*
- *How do you view your future?*
- *Have you learnt any 'life lessons' since your diagnosis?*
- *Were you previously a 'glass half full / empty' person?*

With your experience of living with dementia, what do you think is important for those who have been newly diagnosed to know?

Prompts:

- *What advice would you give to those who have recently been diagnosed?*

Is there anything else you think I should know or anything I need to understand about your experience?

Appendix 14: Interview Summary
Participant 1 - October 2020

Background
Participant 1 was a 67 year old male who was diagnosed with Early-Onset Alzheimer's Disease at the age of 58. He disclosed experiencing multiple bereavements in his life and having seen fatalities at work which he considered to be traumatic.

Diagnosis
He explained the process of being diagnosed with dementia as being 'difficult' and 'long'. Initially his difficulties were misattributed to being indicative of a mental health breakdown (initially depression, and then Bipolar), and he spent the best part of a year being passed between professionals (GP, Psychologist, Psychiatrist) who were treating what was believed to be a serious mental health problem. He spoke of how his wife knew that Bipolar wasn't accurate and so second opinions were sought.

He spoke of how, when initially diagnosed, he believed his life to be over, thinking he would be placed in a home and would not see his family again. Although the diagnosis made sense to his wife (carer), it didn't to him, which he believed to be because of the media representation of dementia and how they only show the latter stages of the disease. This media portrayal gave him a template on how he believed his life with dementia would be.

He explained Alzheimer's as coming with a "superpower" - being invisible, and how people spoke about him, over him and around him, as opposed to to him. He described it as being a lonely place, and drew parallels between how people are currently experiencing Covid and how these are often similar to how people experience the world after being newly diagnosed with dementia. Dementia also signified huge loss for him - from the practical things such as job, driving license, having to downsize the house so they could plan for the future, to the less tangible losses such as friends, respect and identity.

Experience of Post-Traumatic Growth
A post-diagnostic group signalled a change for him in the way that he saw his life with dementia. It opened many doors for him in terms of enabling him to share his experiences with others, both those living with dementia ('inspiring the next generation') and educating those not currently living with dementia. This enabled him to regain his confidence. He acknowledged that it had always been his nature to help others, and he had always been a driven person with a positive outlook on life.

He described his world as different now, but having grown due to receiving the right help and support. His aim is to reduce stigma through education. If he didn't do this work he does, he believes he would have ended up like the media portrayal of dementia. He described comedy and humour as being more important to him since his diagnosis, and of trying to incorporate this into his experience and educational talks, believing that people will be more likely to remember the message if it is delivered with humour. He was able to acknowledge that the work he does is making a difference to people's lives, and gave an example from feedback he had received following a recent talk he'd delivered to staff at a local airport. He spoke of believing

that his work is creating new memories, and that this was ultimately slowing down the progression of his dementia. By taking part in these groups, sharing his experiences with others and delivering various educational talks, this participant felt as though his dementia had enabled him to feel more connected to others, and allowed him to travel to many different countries to meet with a wide variety of people.

He described not liking the term "living well" in relation to dementia, believing it "gives the wrong message". He said it's use suggests it applies to everyone living with dementia, and it doesn't, and spoke of how it gives the impression that all is well and "hunky-doory", which is the wrong impression to give. He also believes the term suggests that PLWD have a choice to either "live well" or not, and this isn't the case. This led on to a conversation about person-centred care and how important this is - 'recognising the person, not the condition'. It was also acknowledged that dementia care is very much a 'postcode lottery' - with some areas not receiving the same high level of care as others.

In terms of things he has learnt from dementia, he spoke of being more caring and listening more to others. He highlighted the importance of not speaking for other people but allowing them to express their own views, in whatever ways they can. He also reflected on how his public speaking has improved his communication skills, enabling him to communicate widely to a variety of audiences. He gave the example of dementia being like a battery in a torch, and how you need both positive and negative energy for a battery to work and to power the torch - this is similar to dementia in that you have to have both the positive and negative experiences to acknowledge the beauty of what you are doing and what you are able to be involved in.

Lessons
- This isn't the end of your life, it's the beginning of your life.
- Don't just listen to a person living with dementia, hear what they say.

Points to Consider / Follow-up
- Planning for the future - what role does this play in PTG?
- Does post-diagnostic care have an influence on PTG?

Reflections
- Interview went well - epitomises what it means to live with PTG following dementia.
- Very emotional interview
- There were occasions where he would talk about 'people living with dementia' as if that did not include him - query whether this is some depersonalisation as a defence, or a language slip due to language symptoms associated with dementia.
- Need more examples?

Appendix 15: Examples from Research Diary

January 2021 (following 5th interview): The first five interviews have now been completed. I have transcribed the first two, which although very time consuming, was a helpful way to immerse myself in the data. The interviews have felt to be a mixed experience so far, with some being really rich and detailed, others not so much. There seems to be a theme running through the interviews which has highlighted the importance of peer support – and in many cases this seems to have been the 'springboard' for growth. At times, it has been challenging to get participants to talk about the growth they have experienced, as their focus seems to be very much on the diagnostic process and how negative and traumatic this was for them. I have been self-critical at times and wondered whether this has been due to my interview style and questioning.

February 2021 (first draft of model): I have now drawn up a finished first draft of the model. It feels similar to a timeline, starting at the point of diagnosis and following participants' journeys through PTG. I am happy with it, although it feels very complex with many different components, and it would be nice to simplify it if possible. The model is currently based majority on men who received a diagnosis of Young-Onset Alzheimer's disease, and so it would be nice to see if the narrative would be different for females and those living with other types of dementia. We have spoken in supervision about how we can recruit these groups to hopefully continue to develop the model.

April 2021 (interview and analysis completed): I have just finished my ninth and final interview! Recruitment, interviewing and analysis has felt like a very long process and it is a relief to have finished this task. Following transcription and analysis of the 7th interview, we had discussions in research supervision and it was agreed that a limited number of new themes were emerging from the data and data saturation was being reached. The decision was therefore made to stop recruiting following the 9th interview. The model is now finalised and has been sent to experts working in the field for feedback.

Appendix 16: Mapping Focussed Codes onto Theoretical Codes

Theoretical Codes
Focussed Codes
Initial Codes

'Welcome to Dementia'
'Experience of Diagnosis'
Misdiagnosed
Labelled as "mad"
Mistrusting Professionals
Negative Terminology
Negative Delivery of Diagnosis
Diagnosis is Traumatic
No Support
Not Being Listened To
Diagnosis is a Hurdle
Long Process
Passed Between Professionals
Kept in the Dark

'Perception vs. Reality': "It happens to others, not me"
Expectation
Stigma
Ignorance
Media Portrayal of Dementia
Something That Happens to Others

'Loss'
Loss of Confidence
Loss of Freedom
Disempowered
Loss of Friends / Social Network
Loss of Identity
Loss of Independence
Loss of Voice
Loss of Worth
Lost Everything
Lost Hope

'Initial Reaction to Diagnosis'
'Depression'
Devastated
Contemplated Suicide

Life's Over
Lonely Place
Giving Up
Shame

'Anger'
Denial
Seeking Proof
Diagnosis Not Making Sense
Alcohol as a Coping Mechanism

'Relief'
Having an Answer
"I'm not mad"
Being able to plan
Gaining Understanding

'Turning Point'
'Connecting with Others'
Peer Support
Shared Understanding
'Bond Like No Other'
Feeling Understood
Family / Carer Support
Post-Diagnostic Support

'A New Beginning'
'Accepting & Adapting'
A Different Part of Life
A New Journey
Back Into the Fold
A Different Person
Completely Different Life
Everything Happens for a Reason
Fighting Dementia
There is a Life After Dementia
Finding New Ways to Cope
Focus on the things you can do, not the things you can't

'Living Well?'
Living as well as you can
Feeling guilty for living well
Better Life
Not the End

Beginning of my Life
Living Well – Captures Experience
High Expectations

‘Finding New Meaning’

‘My Life, My Dementia’

I’m still me
Forgetting the past
Freedom gained from time being limited
Extracting the goodness
I’m happy
I have a good life
Being stoic
Getting on with it
I don’t live with dementia, it lives with me
Making the most of the time that’s left

‘Thank you, Dementia’

Thankful
I’m very lucky
Dementia has been kind to me
Dementia has given me wings
Dementia has given me the opportunity to enjoy life
Dementia has given me opportunities
Strength

‘Finding New Purpose’

‘Paying It Forward’

Being recognised as an expert in my own right
Feeling listened to
Changing the lives of others
Inspiring the next generation of PLWD
It gives me a high
Mentoring
Public Speaking
Delivering education
The ‘selfishness’ of helping others
Sharing my experience / telling my story
It’s too late for me, but there’s time for others
Making a difference
Increase education, reduce stigma and fear
Giving hope and encouragement

‘Trying New Things’
“If dementia doesn’t stop me, nothing can”
Learning new skills
Positive risk taking
Routine
Purpose
Shock at what I can do
Revisiting old hobbies
Finding a creative streak
Getting Involved
Having fun
Humour
Creativity
Finding new ways to communicate
Technology

‘Impact of PTG’
‘Repairing the Loss’
Regaining Confidence
Feeling Worthwhile Again
Feeling Useful
Maintaining Independence
Regaining a sense of pride
Regaining confidence
Speaking up for myself

‘Slowing Down the Progression’
Dementia would’ve taken us
Keeping my brain going
If you don’t use it, you lose it

Fears
‘End Stages’
Becoming a Burden
Impact on Others
Struggle

‘Symptom Progression’
Loss of Dignity
Deterioration

Appendix 17: Participant Feedback Letter

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July 2021

Dear participant,

Research Findings: 'Post-Traumatic Growth in Dementia'

Firstly, I would like to take the opportunity to thank you for recently taking part in the research project looking at post-traumatic growth in dementia. It was a huge privilege to hear your stories and bear witness to your experience of living with dementia, and your participation led to the discovery of some important findings. In total, nine people living with dementia took part. I wanted to take the opportunity to write to you all to inform you of the findings of the research.

The purpose of the research was to investigate post-traumatic growth in relation to living with dementia. Post-traumatic growth is defined as the "positive psychological changes experienced as a result of the struggle with traumatic or highly challenging life circumstances". In the context of this research, dementia was seen as the traumatic or highly challenging life circumstance. The key feature of the experience of post-traumatic growth is that you don't just 'bounce back' from experiencing the trauma, you grow and develop in a way which means your life is, in some way, better than it was before the traumatic experience (i.e., dementia).

The key themes from the research are summarised below:

- **The trauma of diagnosis:** Many of you spoke of being misdiagnosed with another condition, often a mental health condition, fore receiving your confirmed diagnosis of dementia. The length of time it took to receive a diagnosis and the experience of often being passed between multiple different professionals was also discussed. All of you highlighted the negative

language often used by clinicians when a diagnosis is received and how this stripped many of you of any hope you had of learning to live positively with dementia. You all reflected on how the diagnostic process had led to many of you feeling a lack of trust and confidence in professionals and services. Society's view of what it is like to live with dementia, the stigma associated with it, and the loss that often accompanies a diagnosis, all heightened the traumatic experience of receiving the diagnosis.

- **Initial response to diagnosis:** When first diagnosed, you explained feeling either depressed or angry. Many of you also spoke of feeling a sense of relief at finally having an answer for your symptoms. These negative feelings, mixed with a sense of relief, could sometimes cause confusion in how you were adjusting to live with dementia.
- **The 'Turning Point':** Many of you described the importance and positive impact peer support has had on your life. You spoke of how it had enabled you to feel connected to others and form "a bond like no other" with others who understood what you were going through. This created a sense of feeling understood, possibly for the first time on your dementia journey.
- **'A New Beginning':** This theme captured your thoughts on creating a new life for yourselves which involved accepting your diagnosis and adapting to it. Many of you spoke of seeing dementia as a 'new journey' in life.
- **'Finding New Meaning':** Many of you spoke of life having a new meaning since your diagnosis. You talked about living your dementia, your own way, and having a change in outlook. Some of you even thanked dementia for the opportunities it had given you that you wouldn't have had before your diagnosis.
- **'Finding New Purpose':** You spoke of discovering new hobbies and activities since your diagnosis. For all of you, this included being involved in supporting others living with dementia. Many of you spoke of the importance of being recognized as experts in your own right, and how this had given you a sense of purpose.

- **'Impact of Post-Traumatic Growth':** You spoke of how the above themes have repaired many of the losses you experienced when you were first diagnosed. There was a sense that peer support, engaging in meaningful activity, and creating a new meaning for your lives, has slowed down the progression of your dementia, which is holding some of the fears you have at bay.

Clinical Implications

- Post-traumatic growth is possible in those living with dementia.
- Services and professionals need to work hard to shift the negative messages around dementia.
- Service and professionals need to be mindful of the way a dementia diagnosis is delivered, giving special consideration to the language they use.
- Education in dementia needs to be increased for pre-qualified professionals. People living with dementia need to be actively involved in delivering this education.
- Peer support is of paramount importance. Clinical services need to promote and encourage peer support. NHS services need to acknowledge that Third Sector services are best place to offer this support.
- Funding to dementia services needs to increase to cope with the increasing demand and abolish the 'postcode lottery' of support.

I would like to take the opportunity to thank you again for your contribution to the research. I hope the above goes someway to capturing your experience and to doing your story justice.

Best wishes,

Charlotte Cooper

Trainee Clinical Psychologist